# EXPERIENCE AND PARTICIPATION IMPLICATIONS OF DAILY ENHANCEMENT MEANINGFUL ACTIVITY IN PERSONS WITH MILD COGNITIVE IMPAIRMENT

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Experience and Participation Implications of Daily Enhancement Meaningful Activity in Persons with Mild Cognitive Impairment

**Background**: Persons with Mild Cognitive Impairment (PwMCI) battle progressive disengagement from personally meaningful activities that results in functional decline. Little is known about PwMCI experience of engaging in meaningful activities and relationships among MCI stage, confidence, depressive symptoms, and function. Daily Engagement of Meaningful Activity (DEMA) is a multicomponent, family-focused, tailored intervention designed to benefit PwMCI and their caregivers by facilitating goal identification, preserve engagement, and support adjustments to cognitive and functional changes.

**Objectives**: The aims of this secondary analysis were to: (i) describe PwMCI experience of engagement in DEMA, (ii) evaluate for potential relationship among MCI stage, confidence, depressive symptoms, activity type, activity performance, physical function and (iii) evaluate ability of select outcomes to predict change in depressive symptoms and physical function, (iv) determine difference between participants when sub-grouped by ICF level.

**Methods**: Mixed methodology was used to conduct a secondary analysis from the parent study. The parent study used a two-group randomized trial involving PwMCI and informal caregivers participating in the Indiana Alzheimer Disease Center DEMA program. Quantitative analysis (dyads: DEMA N=20, Information Support N = 20) examined outcomes at baseline, posttest and follow-up. Analysis employed: (i) Colaizzi's Method of empirical phenomenology to describe PwMCI experience of

engagement in activity intervention related to perceptions of changes in confidence, activity performance, and physical function; (ii) Pearson's and Spearman's correlation to ascertain relationship; (iii) Linear regression to model the relationship between explanatory and dependent variables; (iv) Independent t-test to determine significant difference in activities and physical function.

**Results**: Qualitative themes confirm improved awareness, adjustment, problem-solving, confidence and optimized function. Significant correlations were found at baseline and posttest for MCI stage, depressive symptoms, activity type and physical function. At posttest, change in self-rated performance predicted change in depressive symptoms. Additionally, those who engaged in activity at the ICF level of participation demonstrated a significant increase in confidence and physical function.

**Conclusion**: Qualitative themes and quantitative results clearly indicate the positive impact of DEMA. Future research should employ a larger, randomized controlled longitudinal trial to ascertain the DEMA impact on physical function, reduction of participation restriction and improved QOL.

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# Chapter I

## Background

### Introduction

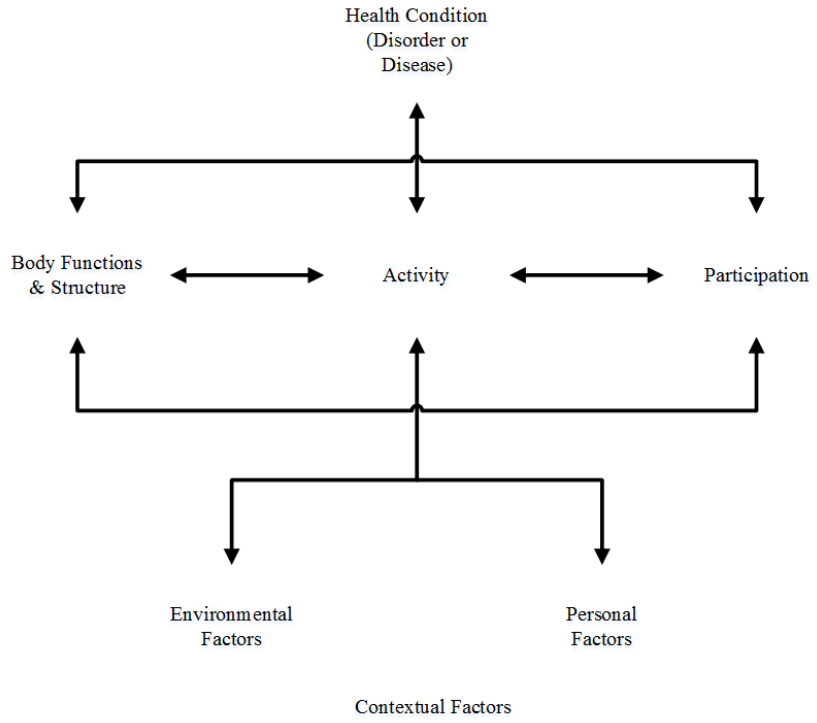
Improvements in population health and skilled delivery of care have significantly extended average life expectancy, begetting a substantial increase in the older adult population defined as age 65 years and above. By the year 2030, the entire baby boomer generation of the United States will be 65 years and older and by the year 2050, older adults will comprise over 20% of the United States' population.[1] Such demographic shifts will be accompanied by wide-ranging implications, including increased prevalence of memory impairment and, more specifically, mild cognitive impairment (MCI).[1,2] Mild Cognitive Impairment, MCI, is currently understood as a transitional state between age-related cognitive changes and the earliest behavioral and clinical signs of Alzheimer's Disease, or AD.[3] Older adults commonly describe changes in memory and perform less well than younger adults across cognitive tasks, particularly those tasks designed to assess memory.[4,5] Such findings suggest that cognitive changes are commonly associated with the aging process, where age-associated memory impairment and cognitive impairment-no dementia are more prevalent than mild cognitive impairment.[6] Yet, the prevalence of MCI is nearly four-times greater than dementia,[7,8] and nearly 16% of the population of older people who have not been diagnosed with dementia meet the current criteria for MCI.[9] Prevalence of MCI ranges upward of 27%, with the preponderance of studies citing approximately 20%.[2,7,10] As many as 48% of persons with MCI (PwMCI) transition to a form of dementia in fewer than 60 months,[3,11-13] with as high as 15% per year converting to AD.[7] Moreover, individuals who meet the criteria of amnestic MCI

develop Alzheimer's-type dementia per year, up to 80% at 5-year follow-up.[14,15] Older adults who experience memory difficulties present with elevated risk of physical functional decline,[16-18] elevated fall risk,[19] emotional distress, depressive symptoms [20,21] and mortality.[22] As researchers and practitioners work to better address the cascade of consequences associated with MCI, theoretical frameworks provide a foundation from which to understand functional ramifications of cognitive changes on everyday activities and independent living. A critical next step is to identify interventions with potential of attenuating multifaceted sequelae of MCI.[23]

Theoretical Overview

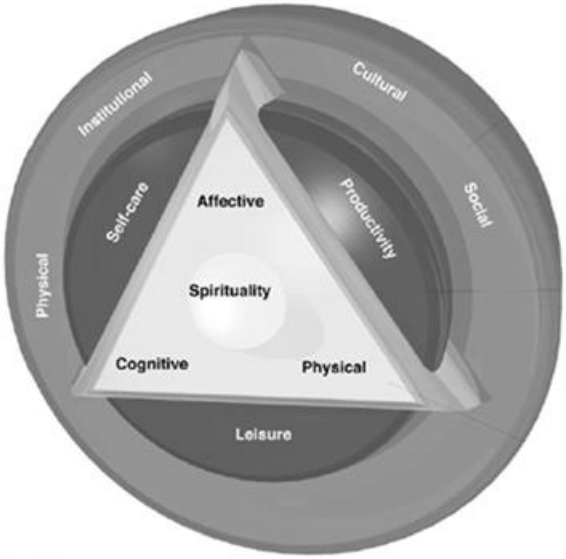
The International Classification of Functioning, Disability and Health (ICF) disablement model provides commonality of language, terms and concepts that span across professional disciplines and settings (Figure 1).[24]

**Figure 1.** ICF model.



The ICF is comprised of two parts, health condition and contextual factors, and five sections (or levels) comprised of body functions and structure, activity, participation, environmental and personal factors.[25,26] Certain enablement models, such as the Canadian Model of Occupational Performance (CMOP) (Figure 2), share commonalities with the ICF and have been used in development of objective measurements such as the Canadian Occupational Performance Measure (COPM).[27-30] The ICF and CMOP models convey biopsychosocial constructs surrounding an individual's health condition, functional status, life roles and interaction with the environment. The COPM affords opportunity to objectify an individual's perception of self-selected, prioritized activities amid efforts to navigate life's health and functional challenges.

**Figure 2.** CMOP.



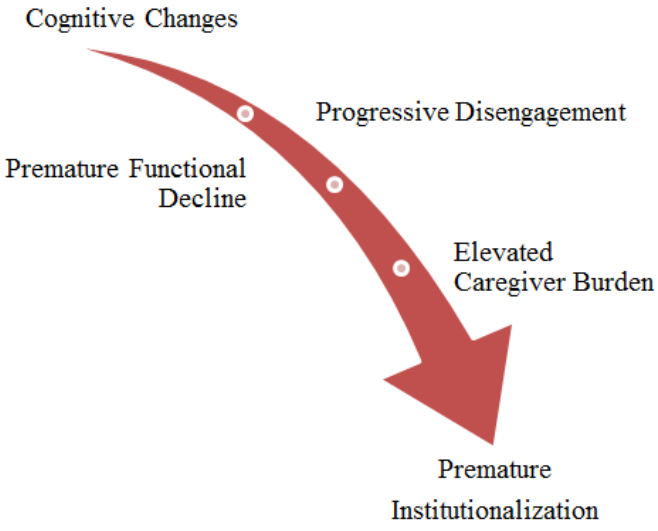

Statement | Significance of Problem

Cognitive changes, when paired with declining functional abilities, exert adverse effects on older adults, are associated with premature need for caregiver assistance and long term skilled care.[17,31] Historically, research efforts have focused on defining health condition, body structure and function, and personal factor implications associated with MCI. Literature shows that functional impairment is an associated feature of MCI, and that the extent of impairment demonstrated by PwMCI is partially dependent on the

degree of cognitive impairment.[6] Research examining temporal relationships between functional and cognitive impairment demonstrates that PwMCI self-report more difficulty with instrumental activities of daily living (IADL) and that, across a five-year interval, deficits in both areas tend to occur simultaneously.[32] PwMCI experience challenges to their functional independence and quality of life (QOL) that may range from difficulty managing finances or handling emergencies to reduced functional performance and elevated risk for adverse events such as falls.[6,33,34] Deficits in instrumental activities of daily living (IADL) are consistently present in PwMCI, particularly related to financial capacity, medication and appointment management, and telephone use.[35] Other typical activities such as shopping, walking and way-finding, traveling and management of everyday technology pose significant challenges to PwMCI.[36-38]

Premature functional decline in PwMCI (Figure 3) is commonly prefaced by progressive disengagement from personally meaningful activities and diminished participation that impacts both PwMCI and their caregivers.[19,39,40]

**Figure 3.** Hypothesized impact of cognitive changes**.**



Studies indicate that cognitive changes and diminished confidence in self-care adversely impact self-care behaviors,[41] while depressive symptoms play a predictive role in IADL such as ability to shop, handle finances and independently use transportation.[42,43] Strains associated with a confirmed diagnosis of cognitive impairment, noticeable functional changes and ambiguity about the future[44] enhances social, financial and functional support burdens on informal caregivers.[39,45] Notably, people with cognitive impairment report more than three times as many hospital stays as those who are hospitalized for some other condition.[46] Cascade effects of functional decline and increased dependency, accompanied by upwards of 48% of PwMCI transition to some form of dementia, frequently necessitate premature admission to alternative living settings or skilled care.[11,15]

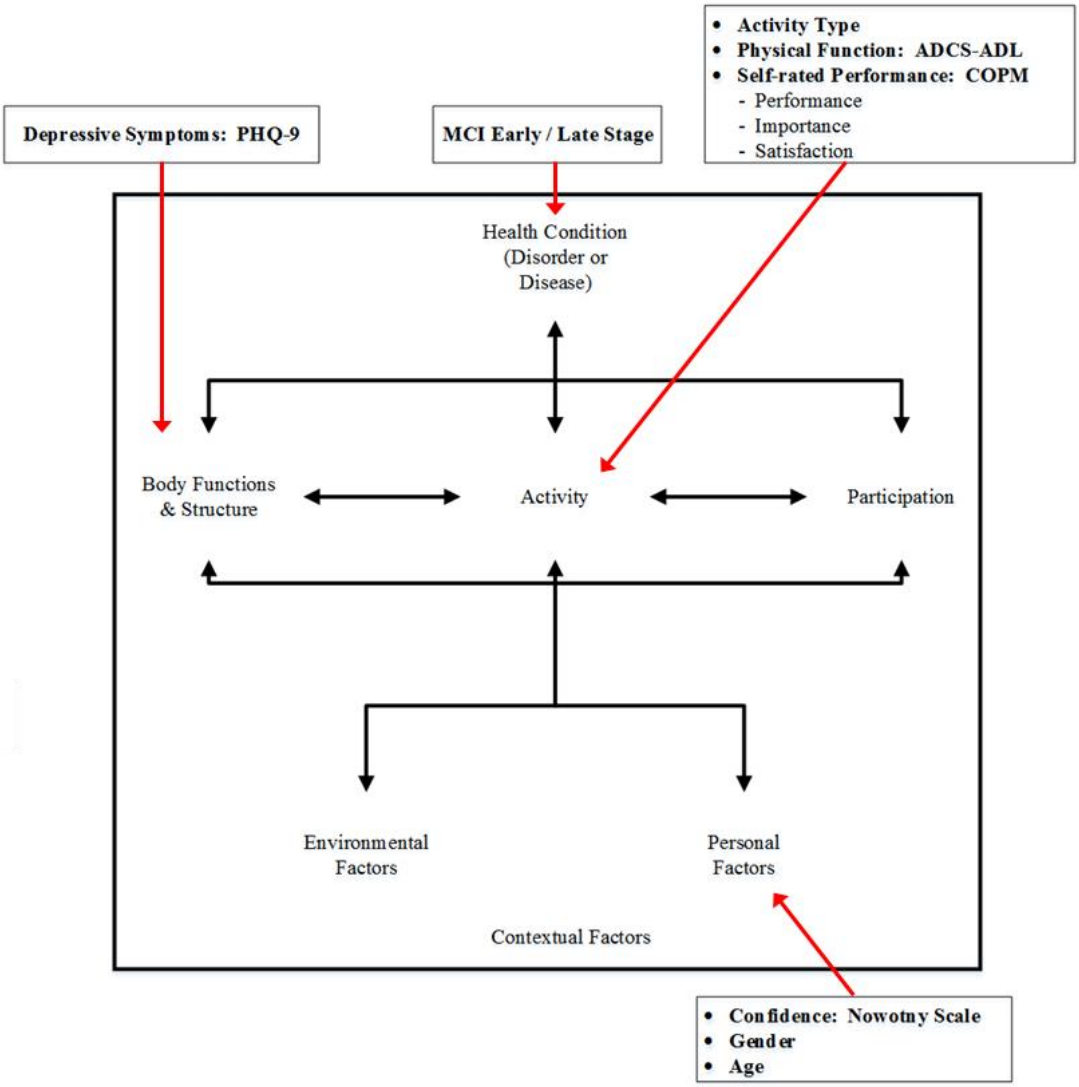
Despite a growing body of knowledge surrounding hallmarks and associated sequelae of MCI, there is little evidence specific to high-impact interventions proven to optimize remaining abilities and attenuate functional decline. Literature supports the efficacy of structured interventions that provide PwMCI and their informal caregivers opportunities to engage in meaningful activities.[47,48] Interventions such as the Daily Enhancement of Meaningful Activity (DEMA)[47-50] program have been shown to foster significant support for PwMCI and their informal caregivers with potential of attenuating functional decline for PwMCI while reducing caregiver burden.[47] However, there remains lack of practitioner insight to PwMCI self-perception of engagement, function, productivity, leisure and evidence-based approaches that foster activity and participation. This void results in scarcity of interventions that optimize meaningful activity engagement to help PwMCI maintain or improve function and quality of life. Moreover,

optimization of experiences of engagement in personally meaningful activities that can be shared with a loved one serve as an anchor of functional preservation for the PwMCI, thereby averting premature placement into long term skilled care.

Through application of qualitative methodology, opportunity exists to employ empirical phenomenology to explore the experience of engagement in meaningful activities of PwMCI who completed the DEMA program. Phenomenological methodology is employed when exploring a particular life experience and phenomenon, the intangibles of which are little-known or realized. Empirical phenomenology adheres to philosophical foundations of intention, consciousness, bracketing and reduction.[51-53] This disciplined, rigorous process yields a description of the phenomenon's fundamental structure.[54] Through this approach, commonalities of lived experience of PwMCI who completed the DEMA program can be discovered.

Through a quantitative approach, opportunity exists to conduct a secondary analysis of a purposive sample of adults older than 60 years, diagnosed with mild cognitive impairment and participating in the DEMA program with their caregivers (parent study: NIH Grant Number: 1R21 NR013755-01; project title: "Meaningful activity intervention for persons with mild cognitive impairment"). Insight into expected relationships and potential effects of health condition (MCI stage), body functions and structure (self-reported depressive symptoms), and personal factors (confidence) on activity type, self-rated performance and physical function will be leveraged to help practitioners develop tailored, person-centered intervention programs to improve daily function and participation while attenuating functional decline (Figure 4).

**Figure 4.** ICF and related DEMA components/outcomes.

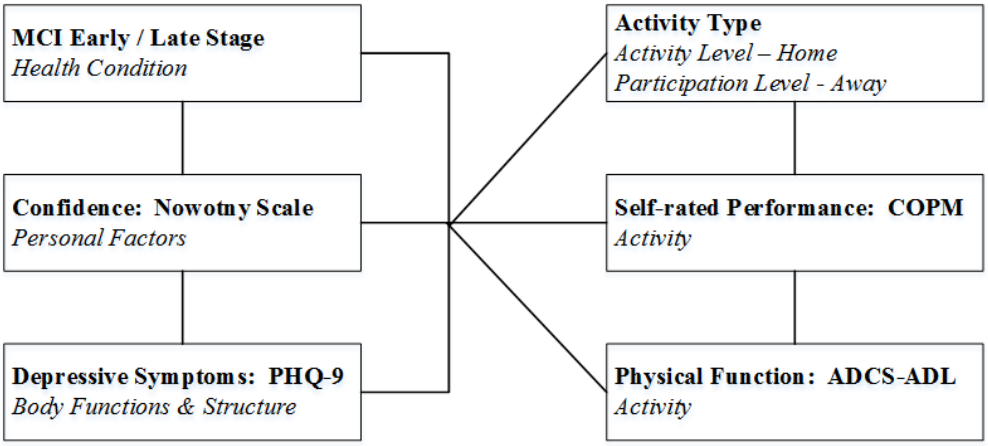



Overall Hypothesis

PwMCI in the intervention group were interviewed at posttest (T2) to elucidate the experience of engaging in the meaningful activity intervention, perceived changes in confidence, activity performance, and physical function. Dyads (PwMCI and caregivers) who completed the DEMA program were measured at baseline, posttest (T2) at two weeks post-intervention and follow-up (T3) at three months post-intervention across all three domains of the ICF model. The inter-relationship of this model (Figure 5) indicates

a potentially significant relationship among confidence (personal factors), MCI stage (health condition), self-reported depressive symptoms (body functions/structure), and activity (ICF activity versus participation level).

**Figure 5.** Hypothesized structural model of inter-related factors.



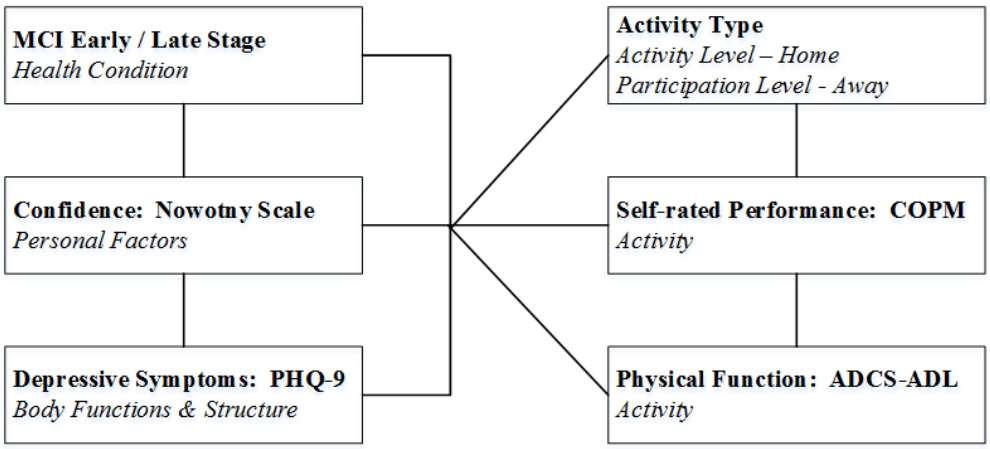

Additionally, change in confidence (personal factors), activity self-rated performance (activity) and physical function (activity), may predict change in depressive symptoms (body functions and structure). Finally, change in confidence (personal factors) may predict change of activity self-rated performance (activity) and physical function (activity).

**Aim 1**: To describe PwMCI experience of engagement in the meaningful activity intervention as related to perceptions of change in confidence, activity performance, and physical function. *Analysis*: Colaizzi Method of empirical phenomenology.

**Aim 2**: In whole group (DEMA and IS) at baseline, evaluate relationships among MCI stage (early versus late), confidence (Nowotny Confidence Scale), self-reported depressive symptoms (PHQ-9), activity type (ICF activity or participation level), self-rated activity performance (COPM) and physical function (ADCS-ADL). *Analysis*: Pearson's product moment correlation, Spearman's rho correlation.

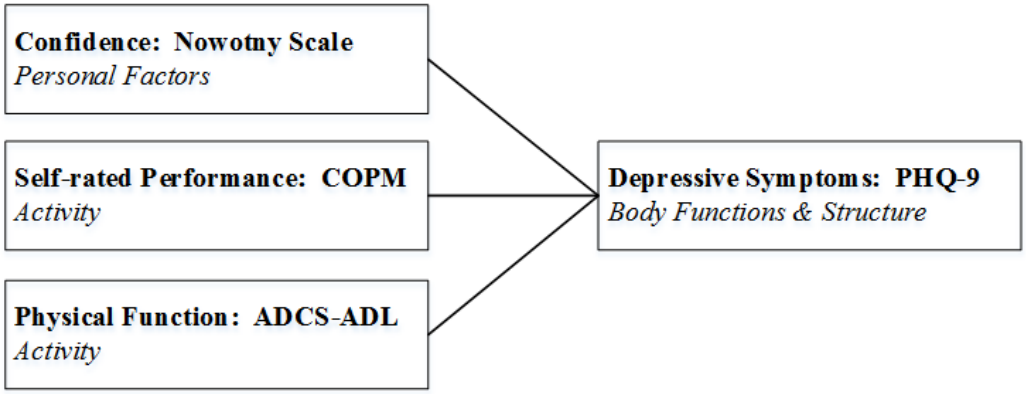
**Aim 3:** In the DEMA group, evaluate posttest (T2) relationships among MCI stage (early versus late), confidence (Nowotny Confidence Scale), self-reported depressive symptoms (PHQ-9), activity type (ICF activity or participation level), self-rated activity performance (COPM) and physical function (ADCS-ADL) (Figure 5). *Analysis*: Pearson's product moment correlation, Spearman's rho correlation.

**Figure 5.** Hypothesized structural model of inter-related factors.




**Aim 4**: In the DEMA group, change (posttest and follow-up from baseline) in confidence (Nowotny Confidence Scale), activity self-rated performance (COPM), and physical function (ADCS-ADL), predicts change of self-reported depressive symptoms (PHQ-9) (Figure 6). *Analysis*: Linear Regression.

**Figure 6.** Hypothesized predictability. Posttest and follow-up change from baseline.



Hypothesis 4.1: Posttest from baseline change in confidence (Nowotny Confidence Scale), activity self-rated performance (COPM), physical function (ADCS-ADL), predicts change of self-reported depressive symptoms (PHQ-9) (Figures 7, 8, 9).

*Analysis*: Linear Regression.

**Figure 7.** Hypothesized predictability. Posttest and follow-up change from baseline.

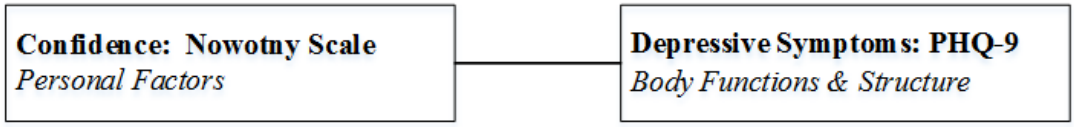



**Figure 8.** Hypothesized predictability. Posttest and follow-up change from baseline.

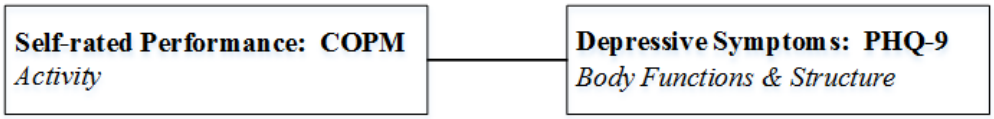
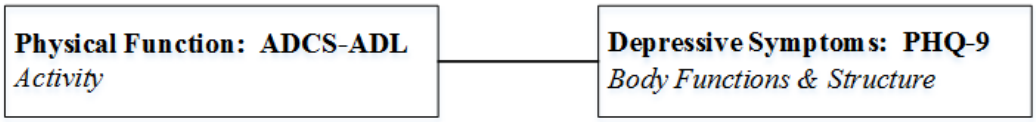



**Figure 9.** Hypothesized predictability. Posttest and follow-up change from baseline.

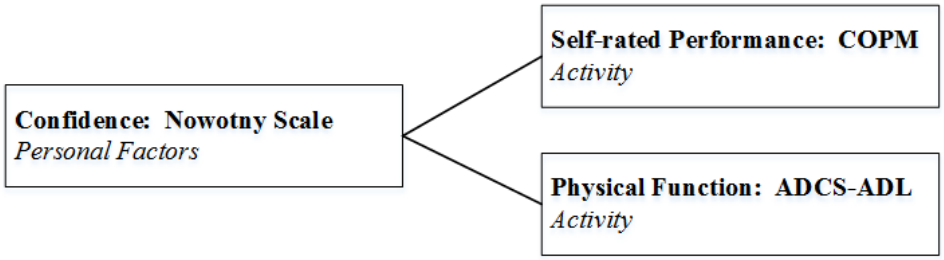



Hypothesis 4.2: Follow-up from baseline change in confidence (Nowotny Confidence Scale), activity self-rated performance (COPM), physical function (ADCS-ADL), predicts change of self-reported depressive symptoms (PHQ-9) (Figures 7, 8, 9).

*Analysis*: Linear Regression.

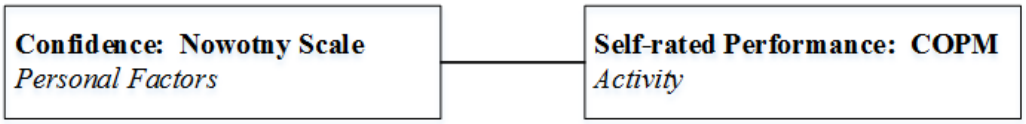
**Aim 5**: In the DEMA group, change (posttest and follow-up from baseline) in confidence (Nowotny Confidence Scale) predicts change of activity self-rated performance (COPM) and change of physical function (ADS-ADL) (Figure 10).

**Figure 10.** Hypothesized predictability. Posttest and follow-up changes from baseline.




Hypothesis 5.1: Posttest from baseline change in confidence (Nowotny Confidence Scale) predicts change of activity self-rated performance (COPM) (Figure 11). *Analysis*: Linear Regression

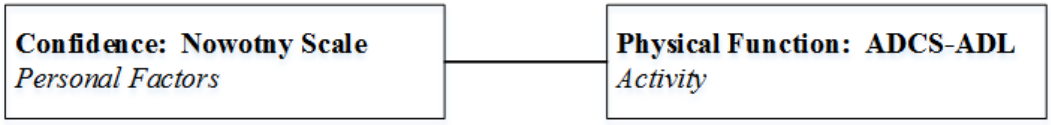
**Figure 11.** Hypothesized predictability.




Hypothesis 5.2: Follow-up from baseline change in confidence (Nowotny Confidence Scale) predicts change of activity self-rated performance (COPM). *Analysis*: Linear Regression.

Hypothesis 5.3: Posttest from baseline change in confidence (Nowotny Confidence Scale) predicts change of physical function (ADCS-ADL) (Figure 12). *Analysis*: Linear Regression

**Figure 12.** Hypothesized predictability.




Hypothesis 5.4: Follow-up from baseline change in confidence (Nowotny Confidence Scale) predicts change of physical function (ADCS-ADL). *Analysis*: Linear Regression.

Delimitations

The scope of this study was limited to PwMCIs and their caregivers (dyads) who presented to the IADC for medical and cognitive evaluation. To be included, PwMCI met established MCI diagnostic and classification criteria. Moreover, PwMCI and caregiver (dyad) dwelt in the same household, spoke English and had telephone access. Caregivers needed to provide primary, unpaid care to their partner and score ≥ 5 on a 6-item Mini-Mental Status Exam (MMSE).

Assumptions

Assumptions were made specific to the following: 1) participant responses to qualitative questions and questionnaire items were truthful, 2) Participants were accurately diagnosed by their respective physicians as having MCI and could be classified as MCI based on definitions provided below, and 3) the results are generalizable to dyads defined as PwMCI and those caregivers who provide primary, unpaid care to their partner (PwMCI).

Limitations

First, this feasibility study was comprised of a small sample size ($n$ = 20 DEMA dyad group, $n$ = 20 IS dyad group). Second, participants (PwMCI and caregiver dyads) were primarily Caucasian with higher education; caregivers of PwMCI were predominantly female and positioned in the role of spouse. Third, PwMCIs' specificity of reporting may have been somewhat limited due to their stage of MCI and potential changes in personal insight. Fourth, follow-up was limited to singular, proximal post-intervention discussion and questionnaire.

Study Significance

The Daily Enhancement Meaningful Activity (DEMA) program is a multicomponent, family-focused, tailored, intervention strategy designed to benefit PwMCI and their caregivers. The DEMA capitalizes on the positive aspects of the interaction between an individual and that person's contextual factors (personal and environmental), affirming that functioning and health are not merely a consequence of condition or disease.[23] Objectifying changes in duration, frequency, self-reported ratings of performance and satisfaction of activities allows evaluation of participants' perceptions of intervention value, lending to refinement of future study designs. Insights into effects of health condition, body function and personal factors on aspects of activity (frequency, duration and self-perceived occupational performance) will help guide practitioners in design and implementation of high-impact interventions, thereby promoting functional preservation, protective effects and improved quality of life. Moreover, scaling and integrating a program such as the DEMA into secondary or tertiary prevention paradigms will serve to attenuate functional decline for PwMCI while reducing caregiver burden and premature placement into long term care.[47]

Definition of Terms

1. Mild Cognitive Impairment (MCI): Considered an intermediate state between normal age-related cognitive changes and the earliest signs of Alzheimer Disease. MCI is characterized by objective evidence of memory impairment without significant deficits in cognitive domains. Signs and symptoms include increased difficulty with concentration, forgetfulness, and decreased work performance. Operationalization of MCI criteria is ongoing.[55,56]

2. Persons with MCI (PwMCI): Persons who experience mild cognitive impairment (MCI) where MCI is understood in accordance with the definition set forth in #1.
3. Amnestic MCI: MCI with memory complaint(s) and deficits.[14]
4. Dementia: A clinical syndrome entailing a range of symptoms associated with a decline in memory or other thinking skills sever enough to reduce a person's ability to perform daily activities. It is characterized by memory impairment, signs and symptoms of aphasia (difficulty with language in all forms), apraxia (impairment in performing learned motor movements), and agnosia (loss of ability to recognize familiar people, objects or stimuli), a decline in physical function, and cognitive impairment.[56,57]
5. Alzheimer's Disease: a progressive, neurodegenerative disease in which the hallmark pathology is the presentation of beta-amyloid plaques and neurofibrillary, or protein, tangles in the brain, compromising the ability of the brain's neurons to communicate with one another. Confidence in diagnosis is based on the following diagnostic criteria: That all criteria are met for major or mild neurocognitive disorder due to Alzheimer Disease, and, that there is insidious onset and gradual progression of impairment in one or more cognitive domains.[55,58]
6. Quality of Life: general well-being of individuals and societies. Health related quality of life is a multi-dimensional concept that includes domains related to physical, mental, emotional and social functioning.[24]
7. Instrumental Activities of Daily Living (IADL): activities often performed by a person who is living independently in a community setting during the course of a

normal day, such as money management, shopping, telephone use, travel in community, housekeeping, meal preparation, medication management.[35]

8. Canadian Occupational Performance Measure (COPM): objectively measures a person's self-perceived experiences of occupational performance (interface between person and environment) through measurement of a client's ratings of activity, satisfaction and performance as correlated to self-care, productivity and leisure (Appendix 1).[27] Clients identify their most important problems in occupational performance and provide a 0 to 10 score for both performance and satisfaction. The tool is commonly used as a method of assessment for directing occupational therapy interventions and measuring client-centered outcomes by detecting change in a client's self-perception of occupational performance over time.[59,60]
9. Mini-Mental Status Examination: Administered in interview style directly to the subject, the MMSE is a brief, global measure of general cognitive functions that includes items that test memory, attention, language, and visuospatial Ability.[61]
10. Nowotny Confidence Subscale: a component of the Nowotny Hope Scale, the Nowotny Confidence Subscale uses a four-point Likert response format of strongly agree to strongly disagree to self-report confidence in one's own ability. Content validity was established by literature review and an expert panel. Concurrent validity of the entire scale was established with the Beck Hopelessness Scale at r = -0.47. The internal reliability was 0.83 to 0.92 (Appendix 2).[62]

11. Patient Health Questionnaire-9 Items (PHQ-9): Extrapolated for use from the Patient Health Questionnaire (PHQ), the PHQ-9 is the depression module, which scores each of the 9 DSM-IV criteria as "0" (not at all) to "3"(nearly every day) (Appendix 3).[63] Items are according to increased frequency of experiencing difficulties in each area covered. Scores are summed and can range from 0 to 27. The score can then be interpreted as indicating no depression, mild, moderate, moderately severe or severe depression.
12. Alzheimer's Disease Cooperative Study-Activities of Daily Living Inventory (ADCS-ADL): a twenty-four item instrument used to assess functional performance and obtain ADL ratings from an informant who spends at least two days per week with the participant. The interview may be completed in person or by telephone. The informant is directed to focus on the past four weeks and on what the patient actually did as opposed to estimating what the patient might be able to do (Appendix 4).[64]
13. International Classification of Functioning, Disability and Health (ICF): Framework for the "description of health and health-related states" that also serves as a classification system that allows for coding.[25] The framework is comprised of two parts: 1) Functioning and Disability and 2) Contextual Factors. The ICF sections and corresponding definitions are detailed in Table 1.

**Table 1.** ICF terms and definitions.[25]

| ICF Section \| Term | ICF Definition |
|---|---|
| **Part One** | Consists of two components comprised of 1) Body Functions, Body Structures and 2) Activity, Participation |
| Body Functions | The physiological functions of the body systems (including psychological functions) |
| ▪ *Impairments* | ▪ Problems in body function or structure as a significant deviation or loss |
| Body Structures | Anatomical parts of the body, such as organs, limbs and their components |
| ▪ *Impairments* | ▪ Problems in body function or structure as a significant deviation or loss |
| Activity | The execution of a task or action by an individual |
| ▪ *Activity Limitations* | ▪ Difficulties an individual may have in executing activities |
| Participation | Involvement in a life situation |
| ▪ *Participation Restrictions* | ▪ Problems an individual may experience in involvement in life situations |
| **Part Two** | Third component, Contextual Factors, consisting of Environmental Factors, Personal Factors |
| Environmental Factors | Physical, social, attitudinal environment in which people live and conduct their lives. May serve as barriers to or facilitators of the person's functioning. |
| Personal Factors | Particular background of an individual's life and living that are not represented elsewhere in the ICF. Factors may include may include gender, age, race, lifestyles, habits, education and profession. |
| Functioning | The umbrella term used for all three levels, namely body functions and structures, activity and participation |
| *Disability* | The umbrella term for the problems an individual may experience in functioning, namely impairments, activity limitations and participation restrictions. "It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)". |

# Chapter II

## Review of the Literature

### Parent Study

This secondary analysis employs data from a parent study - NIH Grant Number: 1R21 NR013755-01; project title: "Meaningful activity intervention for persons with mild cognitive impairment"; name of grantee organization: Indiana University-Purdue University Indianapolis; project period start date: 07/01/2012; project period end date: 06/30/2015. The parent study was grounded in findings from two phenomenological studies, a three-phase DEMA development study and a randomized controlled trial pilot study.[47,49,50,65-67] Pilot study findings confirmed content validity,[49] high acceptability and feasibility, as well as promising potential benefits of the multicomponent Daily Enhancement of Meaningful Activity (DEMA) intervention.[47] The DEMA is an innovative, tailored intervention approach that incorporates (a) gerontological theory;[68] (b) the model of human occupation;[69] (c) components of problem-solving therapy; [70] and (d) persons with mild cognitive impairment (PwMCI) and caregivers' experiences.[66,67] The DEMA is intended to facilitate goal identification and achievement, preserve engagement in meaningful activities, and support adjustments to changes experienced over time.[47] The parent study used a two-group randomized trial involving PwMCI and their informal caregivers participating in the Indiana Alzheimer Disease Center (IADC) DEMA program. Parent study aims entailed evaluation of the feasibility of the study of MCI patient/caregivers, estimation of effect sizes for DEMA on MCI patient and caregiver outcomes and evaluation of PwMCI and family caregivers' satisfaction with

and perceptions of the DEMA intervention or the information support (IS) control group.[47,50]

MCI Overview | Diagnosis

Mild cognitive impairment (MCI) is considered a transitional state between age-related cognitive changes and the earliest behavioral and clinical signs of Alzheimer's Disease, or AD.[3] Peterson and colleagues were pioneers who introduced MCI and a well-known classification system intended to identify individuals at risk for developing AD: 1) the presence of a memory complaint, 2) normal activities of daily living, 3) normal general cognitive functioning, 4) memory impairment relative to age peers and 5) the absence of dementia.[58] Characterization of MCI evolved to incorporate the following: 1) change in cognition in comparison to an individual's previous level, 2) objective evidence of low performance in one or more cognitive domains that is greater than expected for the person's age and educational background, 3) does not extensively interfere with daily activities, yet performance of complex functional tasks such as paying bills, meal preparation or shopping is less efficient than previous. Basic activities of daily living (BADL) are essentially preserved with minimal aids or assistance; 4) is not explained by delirium or a major psychiatric disorder.[71] Features of MCI include amnestic MCI (aMCI), single-domain non-amnestic MCI and multiple domain MCI.[72] The amnestic type is considered a prodromal stage of dementia, primarily presenting with memory impairment.[58,73] However, general cognitive function and daily activities remain typical. Non-amnestic MCI is characterized by cognitive changes and motor performance changes, while memory appears unaffected.[58,74] In multiple-domain MCI, both memory loss and cognitive decline occur.[72] Currently, there is no known cure, no

verified strategy to stop or reverse MCI.[72] In absence of a known cure, the rising incidence and prevalence of MCI - along with an elevated risk of conversion to dementia – reveals the growing requisite to address PwMCIs' and caregivers' diverse and complex needs while attenuating associated sequelae like functional decline.

Prevalence | Conversion

Cognitive impairment is a rising challenge in the elderly that is associated with increasing age, exhibiting an occurrence rate of approximately 21.5-71.3 per 1,000 person-years in older adults.[75] Mild Cognitive Impairment (MCI) affects greater than one fifth of the population over the age of 65.[2,10] Population studies around the world indicate that MCI ranges from 3% to 42%,[75] while reported incidence in clinical settings ranges from 6% to 85% .[72]

Not everyone who presents with MCI develops dementia and research suggests that some PwMCI may improve over time.[76,77] However, up to 48% of persons with MCI (PwMCI) transition to a form of dementia in fewer than 60 months,[3,11-13] with as high as 15% per year converting to AD.[7] Studies show that age is strongly associated with risk of MCI conversion to dementia.[75,78] Specific to the memory care clinical setting and in accordance with commonly used diagnostic criteria, the risk for dementia at 10-year follow-up ranges are noted in Table 2.[78,79]

**Table 2.** Risk of conversion to dementia.

| Age Range (years) | Percent (%) Range of Risk for Dementia at 10 year follow-up |
|---|---|
| 40 - 54 | 6% |
| 55 - 69 | 37% – 52% |
| 70 - 85 | 77% – 100% |

Other investigations confirm that predictive accuracy in clinical practice is best for amnestic MCI in persons 70 to 85 years but is otherwise limited.[80] Health studies focused on older adults indicate significant presence of co-morbid conditions that increase with age.[81,82] Meanwhile, older adults with MCI face co-existing challenges with IADL and elevated risk of conversion to dementia. Such challenges, individually and when mixed with co-morbid threats to health and functional status, intensify dependency and accelerate social and functional support burdens on informal caregivers and the healthcare system as a whole.[10,39,45]

Public Health | Policy Considerations

When discussing her experience of Prescribed Disengagement™ following a diagnosis of dementia, Swaffer asserts that society as a whole must view persons with dementia (PwD) "as whole people, living with disabilities, as the same way people are sight impaired or in a wheelchair".[83] From societal and health policy perspectives, the World Health Organization and Alzheimer's Disease International[84,85] released an extensive report in 2012 to address dementia, specifically Alzheimer's Disease, with the stated intent to "raise awareness of dementia as a public health priority, to articulate a public health approach and to advocate for action at international and national levels based on the principles of inclusion, integration, equity, and evidence."[85] That same year, the U.S. Department of Health and Human Services released the original *National Plan to Address Alzheimer's Disease,*[86,87] followed by annual updates in 2013 and 2014.[88-90] The U.S. plan incorporates elements such as dementia-capable into policy, while frameworks and policies of other countries incorporate dementia-friendly.[85,87] Dementia capable is commonly understood as "an ability (or combination of staff knowledge, skills

and competency as well as available programs and services) to fulfill the needs of PwD and their caregivers."[86,89] In the U.S., dementia capable is linked to a two-step approach comprised of inclusion of persons with dementia into the disability community and promotion of inclusion into society at large through being a member of the disability community.[89,90] Dementia positive is a proposed third concept, defined as "positivity towards dementia with an international emphasis on strength finding, manifesting through attitudes, beliefs, communication and behaviors."[84] Dementia positive relates to needed changes in societal attitudes, behaviors, beliefs and communication with the intent of genuine social inclusion of PwD and their families. While policies, societal plans, funding and research for AD have improved, it is not well understood to what extent AD study findings can be extrapolated to MCI.[91,92] Implications of MCI remain predominantly understood at the individual, caregiver and health service provider levels.

Functional Implications

Meta-analyses and systematic reviews of nursing home admission predictors identify cognitive impairment along with IADL and ADL declines as key precursors to institutionalization.[31,93,94] Studies also demonstrate significant associations between MCI, IADL performance and everyday function.[17,95,96] Increased difficulty with IADL that are specifically associated with 'high cognitive demand' is strongly associated with MCI.[97] Analysis of PwMCI accuracy of self-reported functional abilities demonstrates appropriate congruence between self-report and objective performance with exception of PwMCIs' self-estimated financial abilities.[98] Studies using performance-based tools to assess global instrumental activities of daily living in PwMCI compared to healthy controls show that PwMCI require more time to complete multi-tasking in real-world

settings and make more errors while problem-solving subtasks.[99] Specifically, PwMCI demonstrate impaired speed and accuracy with solving challenges related to shopping, finances, medication, telephone use and locating information on food labels.[100,101]

PwMCI self-report difficulties using a telephone, keeping appointments, handling finances, managing medication(s), talking about recent events and using household appliances.[96,102] Several studies confirm three areas of significant impact of MCI on IADL: (i) PwMCI are more likely to be more restricted in IADL than normal controls but less likely than individuals with dementia, (ii) mild IADL restrictions remain associated with elevated risk of progression to dementia and (iii) persons classified as normal on neuropsychological tests – yet present with IADL restrictions – remain at higher risk for dementia than PwMCI without IADL restrictions.[96,97,103-105] Studies using informant-reporting tools specific to PwMCI and IADL abilities confirm performance-based findings of MCI-associated changes in domains of telephone use and medication intake. They also reveal challenges with meal preparation, management of belongings, keeping appointments, talking about recent events and performing leisure activities and/or hobbies.[103,106-108]

On a personal level, PwMCI face significant challenges to navigating the world in which they are expected to contribute. Such challenges place PwMCI in a position of battling functional decline, depression and progressive disengagement from personally meaningful activities that consequently impacts the PwMCI-caregiver relationship.[19,39,40]

Insight | Emotions | Coping

PwMCI report uncertainty about the nature of an MCI diagnosis, and demonstrate a tendency to minimize perceived risk of conversion to AD.[109,110] Assessment of

psychologic reactions, perceptions of illness and coping responses indicate that both PwMCI and caregivers viewed mental and physical exercise, optimism, dietary changes, and stress reduction as legitimate prevention approaches to reduce conversion to AD.[109] One U.S. cross-sectional population-based study revealed nearly 20% prevalence of depression in community-dwelling PwMCI.[111] Qualitative studies reveal PwMCI may experience an array of emotions that include shock, anger, decreased self-confidence and embarrassment, feeling of loss of control, fear of becoming a burden to others, anxiety, sadness, frustration and anger.[109,112,113]

Studies linking PwMCI with caregiver informants demonstrate that PwMCI exhibit reduced insight into personal cognitive changes and functional challenges when compared to informant reports.[109,114,115] Caregivers' experiences across the emotional spectrum may include shock, anger, guilt, anxiety, frustration, sadness, loneliness, helplessness, worry and uncertainty.[44,67,110] Depressed mood can occur in nearly a quarter of all MCI caregivers,[113] which is greater than in non-caregivers of a similar age (~13%) but less than in AD caregivers (~40%).[116]

Swaffer[83] brings personal experience to her discussion of the emotional toll that accompanies a diagnosis of dementia. Furthermore, she highlights the importance of adopting a disability model of care that supports optimized engagement and functional strategies.[83] Currently, PwMCI and caregivers report strategies for coping that include practical solutions to challenges associated with memory changes such as keeping a calendar and written reminders of appointments, encouragement and partnering to plan activities.[44,113] Studies show that PwMCI and caregivers tend to employ emotion-focused

(e.g. acceptance) and problem-focused (e.g. external and internal memory strategies) coping versus dysfunctional ones (e.g. self-distraction).[109,117]

Investigation of the relationship of hope to coping mechanisms reveals clustered themes around goal orientation (e.g. "I have a sense of direction." I have short, intermediate and long range goals."), positive emotions (e.g. "I am able to give and receive caring and love." I can recall happy and joyful times."), and a sense of possibility that is future-oriented ("I have a positive outlook towards life." "I believe that each day has potential.").[118] As they navigate multifaceted impacts of facing the diagnosis, PwMCI and their caregivers shoulder on-going challenges to fulfillment of personal, family and societal roles.

Participation | Quality of Life

PwMCI and their caregivers report changes in self-perception, relationships, daily interactions, self-management and future-oriented decision-making that impact overall participation and perceived quality of life.[33] PwMCI self-report significant declines in quality of life that are frequently associated with neuropsychiatric symptoms and functional decline.[21,33] Further, evidence suggests significant relationships between Health related quality of life (HRQOL) and informant/self-rated ADLs in PwMCI.[119]

Memory changes frequently contribute to PwMCI abandonment of role-related responsibilities and activities they enjoy, such as managing finances or participating in leisure activities and social events.[38,117] Despite risk of disengagement, PwMCI and their caregivers report potential to optimize role-related participation.[113,120] PwMCI describe "finding ways to hold onto a sense of being able"[113] through preserved abilities like self-

care, maintaining the home environment through daily routines such as taking out the trash, completing lawn care, or preparing the home for holiday gatherings.[113]

Lived Experiences of PwMCI │Caregiver

While many MCI studies focus on pathology, biomedical aspects and functional status,[3,6,71,100,106] a growing body of qualitative studies that employ empirical phenomenology and grounded theory help shed light on lived experience and perspectives of PwMCI and their informal caregivers.[66,67,117,121,122] Phenomenological methodology is employed when exploring a subjective life experience and phenomenon, particularly when the intangibles of which may be complex, little-known or realized. It is useful to describe affiliated experiences, the commonalities of which are consequently understood as the essential structure. From the essential structure, key factors are realized.[123,124] Grounded theory methods involve techniques such as gathering of focus group and survey data, coding and analyzing in order to inductively generate theory grounded in the data themselves versus testing hypotheses or preexistent theories.[122]

PwMCI describe experiences of being diagnosed and living with MCI as a growing awareness of changes in abilities accompanied by a process of distinguishing current-day memory changes from previous memory skills, and ambiguity surrounding diagnoses of MCI and AD.[66,121] They report consequences associated with a diagnosis of MCI including, but not limited to, anxiety and loss of self-confidence, feelings of irritation and anger toward others and abandonment of leisure activities.[117] As capabilities change, PwMCI describe increased awareness of challenges with complex or multi-tasking and social difficulties such as tracking conversations while in a group of people.[66,117] Parallel to ongoing changes, PwMCI draw from past abilities and successes

while voicing gratitude and determination to use "aspects of their past meaningful life activities to live as well as possible and contribute to the future."[66] Coping may involve emotion-oriented, problem-focused and avoidant strategies.[117] Despite increasing awareness of having MCI and the consequences, PwMCI describe efforts and a sense of "still being able",[113] as they continue to process information, solve problems, master responsibilities, stay connected and maintain purpose through on-going accomplishments. Simultaneously, they describe the need to resist entrapment in the diagnosis and retain a sense of self.[113] Additionally, study participants with MCI voice that memory loss is yet another age-related challenge to surmount, like hearing loss or reduced mobility.[125] As with any health challenge, lived experience and consequences accompanying diagnosis-related changes seldom occur in a vacuum.

Caregivers for PwMCI disclose that they experience heightened burden and negative impact on emotions directly associated with caregiving.[126] Spouse caregivers of PwMCI share an unfolding realization that their loved one's cognitive changes are persistent and progressive. They report that on-going recognition of their spouse's decline accompanies a sense of loss and heightens events of random emotional distress. Consequently, caregivers report a "shrinking world" that impacts activities, finances and social relationships.[67,127]

When asked about views on what getting involved in activities outside the home means for someone with dementia, caregiver informants identify social connectedness, physical health and mental stimulation as significant benefits. Caregiver response frequencies and co-occurrences also indicate that the perceived degree of benefits of activity vary by stage of disease.[127]

Mild cognitive impairment is not experienced in isolation. Consequences of the diagnosis impact both PwMCI and caregiver social and societal roles, as well as quality of life. Absence of a known cure further positions PwMCI and their caregivers in need of innovative support to engage in a process of fashioning an individual and shared sense of identity within their social context.[128] Understanding both PwMCI and caregiver perspectives helps guide investigators and practitioners to better design, test and implement interventions that extend beyond a medication regimen.

Non-Pharmacologic Interventions

The U.S. Preventive Services Task Force identifies specific need for more research on screening and treatment of MCI.[129] Research affirms that engagement in meaningful activities in PwD who reside in skilled nursing settings contributes to a sense of well-being, reaffirms identity and belonging, and enhances a sense of ability to do things that they enjoy.[130-133] Additionally, adaptation and tailoring of activities to a person's abilities improves self-esteem and overall participation in activities.[134,135] In community-dwelling PwD, meaningful activity may include cognitive, physical, social, household or leisure activities that remain congruent with previous interests and preserve "a sense of self and social-identity with the aim of deriving joy, purpose, and improved health."[127]

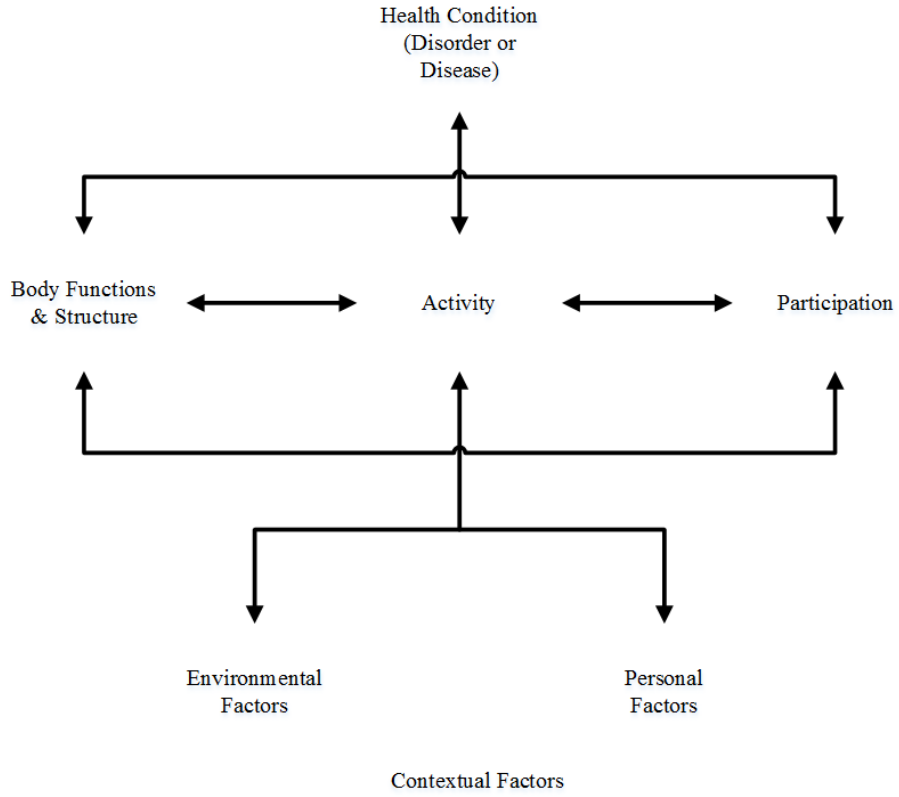
Different than recent dementia study findings, early and subsequent MCI intervention designs were primarily unidimensional - limited to PwMCI versus caregiver inclusion – and largely focused on memory or physical activity.[136-138] Dyadic interventions designed to provide early diagnostic counseling for family caregivers and care receivers demonstrate benefit from structured interventions that focus on acceptance

of diagnosis, management of memory changes and care planning for future needs.[48,139] Although such interventions demonstrate promise, they remain limited in scope. In fact, little is known about likelihood of response to multicomponent intervention. In contrast to unidimensional approaches, the Daily Enhancement of Meaningful Activity (DEMA) program is a multicomponent, dyadic, tailored intervention intended to help PwMCI and their caregivers work together to identify and meet goals, remain engaged in meaningful activities, and adapt to changes over time.[47] Multi-dimensional, dyadic, tailored interventions have been shown to foster significant support for PwMCI and their informal caregivers through expansion of PwMCIs' capacity to participate in meaningful activities, reduction of care burden and improve PwMCIs' and respective caregivers' well-being and quality of life.[47,49] Such interventions may serve to improve identification of important activities, self-reported performance, participation and satisfaction. On-going efforts to innovate and expand interventions for MCI traverse multiple health disciplines, further reinforcing the value of the ICF model to inform on-going intervention designs and coalesce discussions of findings.

Theoretical Framework

Building on the DEMA study framework, this secondary analysis employs the International Classification of Functioning and Disability (ICF) as a guiding theoretical model. The ICF biopsychosocial model provides commonality of language, terms and concepts that span across professional disciplines and systems (Figure 1).[24]

**Figure 1.** International Classification of Functioning and Disability (ICF) model.



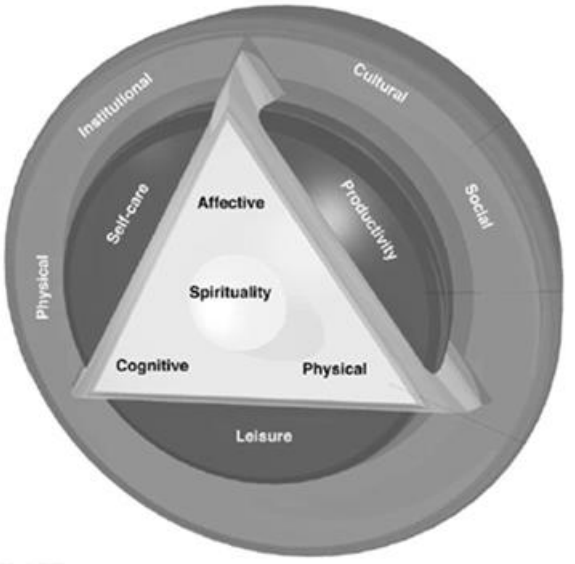

It consists of two parts and five levels that illustrate interconnections and influences among components. Body function, body structures and activity participation comprise part one, where activity limitations and participation restrictions are viewed as multidirectional between the different levels. [25,26] Body structures are defined as anatomical parts of the body while body functions are understood as physiologic in nature.[23,140] Activity is defined as the execution of a task or action while participation is defined as involvement in life situations.[25]

Specific to contextual factors, personal and environmental factors comprise part two, where contextual factors 'make up the physical, social and attitudinal environment in which people live and conduct their lives.'[24] Notably, personal factors do not included a specific list of items but instead encompass features that influence how disability is

experienced by the individual.[23,141] Globally, functioning and health denote the interactions between an individual and that individual's environmental and personal factors. The ICF provides a theoretical framework of disablement that provides a conceptual basis for the definition and measurement of disability, as well as organization and documentation of functional change.[142]

Conversely, discipline-oriented clinical models that share commonalities with the ICF provide frameworks of thought. These clinical models foster discovery of innovative, high-impact interventions that promote activity and participation, thereby improving functioning and health in PwMCI. Models related to occupational performance are akin to the ICF model where occupational performance reflects personal and environmental aspects of activity and participation.[143] Stemming from the clinical discipline of Occupational Therapy, the Canadian Model of Occupational Performance (CMOP) (Figure 2) illustrates an enablement model of occupational performance as dynamic and interdependent interactions between the person, the occupation and the environment where occupational engagement is the desired outcome.[28-30,69] This model provides a conceptual framework by which to define prominent underpinnings of occupational performance - such as self-care, productivity and leisure.[29] The Canadian Occupational Performance Measure (COPM),[27]

**Figure 2.** CMOP.



provides a means to objectify a person's self-perceived experiences of occupational performance through measurement of a client's ratings of activity, satisfaction and performance as they correlate to self-care, productivity and leisure.[27] Measurement of occupational performance affords meaningful insights to self-perceived aspects of activity and participation with respect to contextual factors, taking into consideration both the performance itself and the individual's reported satisfaction with performance of self-selected activities.

Summary of Gaps | Improved Scientific Knowledge

A substantial body of knowledge attests to functional implications of MCI as well as characteristics and experiences of PwMCI and caregivers. While evidence for interventions focused on unidimensional problems such as memory or physical activity is ever-increasing, there remains a compelling need for evidence specific to multi-faceted supportive care interventions for PwMCI and their caregivers.[66,67,144] Moreover, opportunity exists to increase insight into interactive influences among health condition, body function and personal factors, and aspects of activity (frequency, duration and self-perceived occupational performance). Findings from investigation and discovery specifically related to the aforementioned will aid to better support practitioners in design and implementation of high-impact interventions that yield prolonged functional preservation and improved quality of life.

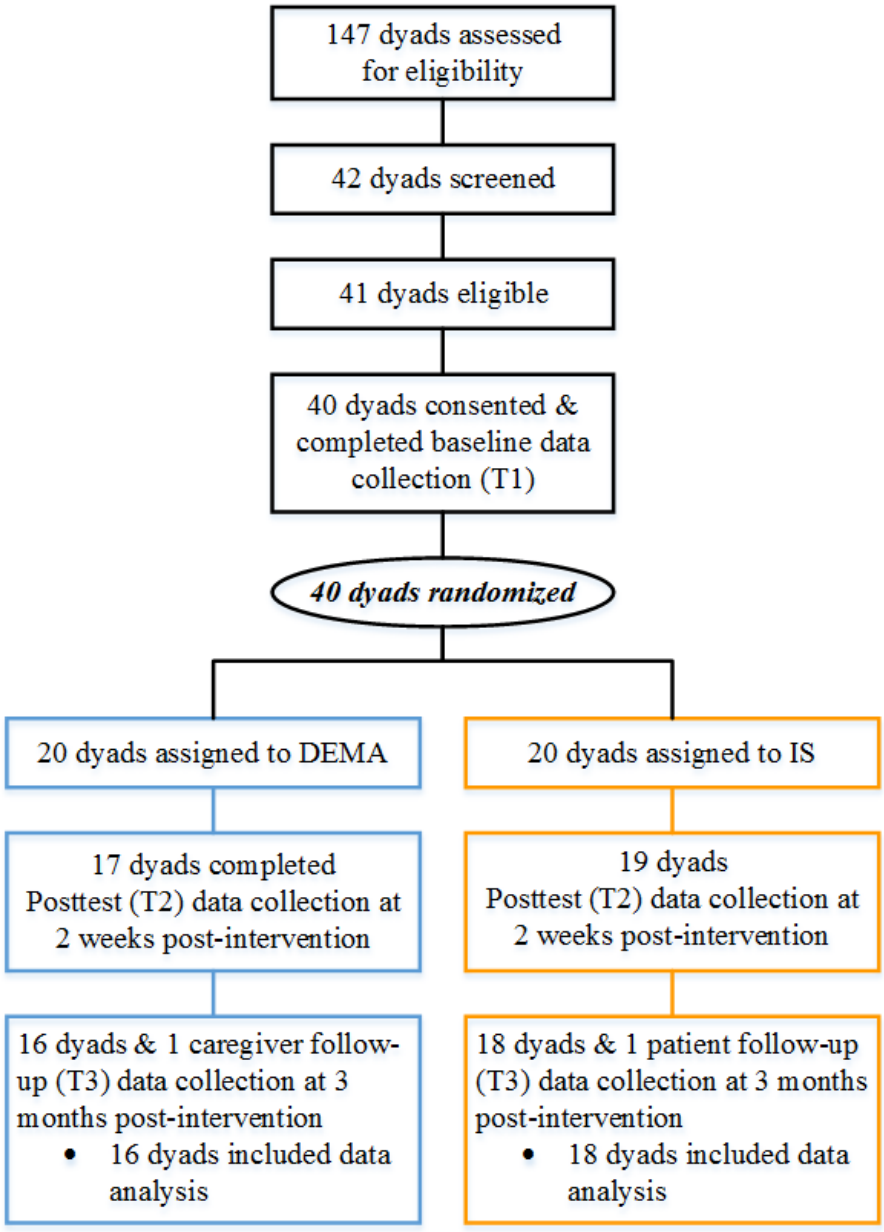
# Chapter III

# Methods

## Study Design

The parent study design entailed a two-group randomized trial involving PwMCI and their informal caregivers participating in the Indiana Alzheimer Disease Center (IADC) DEMA program: NIH Grant Number: 1R21 NR013755-01; project title: "Meaningful activity intervention for persons with mild cognitive impairment"; name of grantee organization: Indiana University-Purdue University Indianapolis; project period start date: 07/01/2012; project period end date: 06/30/2015. Pursuant to consent and completion of baseline measures, 40 MCI patient/caregiver dyads were stratified by Patient Health Questionnaire-9 items (PHQ-9)[63] patient depression scores and randomized to either Daily Enhancement of Meaningful Activity (DEMA) or an Information Support (IS) group. After randomization (Figure 13), both study arms received six bi-weekly sessions (2 sessions face-to-face and 4 via phone) over three months, followed by two additional measurement sessions. Posttest (T2) and follow-up (T3) data were collected within two weeks post-session six and at three months post-intervention. Post-session collection was intended to: (1) identify immediate and carry-over effects of DEMA and (2) ascertain whether patients would engage in meaningful activities with family caregiver support at home (feasibility, satisfaction). Additionally, separate qualitative interviews were conducted with DEMA patients and caregivers after completion of follow-up measures. Parent study methods will first be addressed followed by clarification of methods particular to the secondary analysis.

**Figure 13.** DEMA study schema.




Study Participants

MCI Patient/Caregiver Inclusion: In order to be eligible for the study, both persons with mild cognitive impairment (PwMCI) and caregivers were required to consent to participated and possess a working phone in the home or daily access to a telephone. PwMCI inclusion criteria was comprised of the following: 1) aged 60 years or

older; 2) spoke English; 3) presented with both caregiver reported, clinically significant decline in cognition and practitioner-detected cognitive impairment on the standardized health exam; 4) presented with at least one cognitive assessment score below the 7$^{th}$ percentile; and 5) presented in the normal range in performance of daily living tasks based on informant interview information, which indicated that impairment did not rise to the level of dementia. Family caregivers were eligible providing: 1) were adults ≥ 21 years of age; 2) presented with primary responsibility for providing unpaid care to a PwMCI, along with monitoring for safety and providing social support; 3) were able to read and speak English; 4) were oriented to persons, places and time (presenting with a 6-item mini-mental status exam, or MMSE, score ≥ 4).[145]

MCI Patient/Caregiver Exclusion Criteria: PwMCI and family caregivers were excluded if: 1) the PwMCI or family caregiver presented with a diagnosis of bipolar disorder or untreated schizophrenia; 2) the family caregiver had significant cognitive impairment that would hinder participation (6-tiem MMSE < 5).[145]

Sample Size: Estimations yielded sufficient effect size at 12 dyads.[146-148] The intent of the parent investigation was a pilot feasibility study focused on effect size estimation to inform sample requirements for a future randomized trial.[50] Consequently, power was not relevant for in-depth consideration at the time of the parent study. Following baseline assessment, thirty-six PwMCI-caregiver dyads were enrolled (18 per group) with the aim to retain a final sample of 32 dyads (16 per group).

Procedures

Recruitment | Consent | Retention: The target sample of dyads was comprised of volunteers recruited from the Indiana Alzheimer Disease Center (IADC), Clinical Core

and/or the local Chapter of the Alzheimer Association. Volunteers were PwMCI aged 60 and older and family caregivers. Certified clinical research coordinators employed the eligibility checklist to identify potential participants, provide the initial study introduction brochure and confirm eligibility. Following, the program manager contacted and explained the study to the PwMCI and family caregivers. Upon confirmation of interest, the program manager secured completed consent forms subservient to human subjects review committee requirements.[149] The study Principle Investigator and program manager monitored recruitment and adherence to strategies for participant accrual and retention.[150-152] Strategies for accrual and retention of minorities included: 1) cultural competence training for all study staff to optimize African-American participant recruitment; 2) large print material and attendance at the IADC, local Alzheimer Association, local Diabetes Association and Indiana Minority Health Coalition meetings, paired with frequent clinic staff contact to advertise and mitigate risks of misunderstanding specific to the study intent, design and participation criteria; 3) posting the study on the Alzheimer's Association TrialMatch website; 4) face-to-face contact with participants during the two initial sessions to facilitate trust and confidence in the relationship with the intervener and staff; and 5) offering flexibility and convenience in scheduling.

Data Collection | Randomization: Subsequent to consent, convenient times were arranged by the program manager for patient-dyads to complete baseline measures by phone. A trainer evaluator administered measures via telephone interviews in a quiet/private setting and remained available for questions following completion of the data collection. Subsequent to conveyance of the calculated PHQ-9 depression scale

scores to the statistician,[63] the patient-caregiver dyads were randomly assigned to the DEMA or the IS group via a block-randomized approach stratified on a depression score cut-point of five. Statistical Analysis Software (SAS) PROC PLAN ≥ version 9.3 was used to determine the randomization.[153] The first session was scheduled following randomization and the intervener had knowledge of the PwMCI-caregiver randomization status.

Sessions were audiotaped to monitor evaluation and treatment fidelity. An evaluator who was masked to evaluation randomization status administered posttest (T2) measures within two weeks post-session and follow-up (T3) measurements at three-months post-session six. PwMCI and caregivers separately completed a post-program evaluation in both the DEMA and IS groups. Specific to the DEMA group, separate qualitative interviews of PwMCI and caregivers were accomplished via audio-taped phone interviews conducted by trained research assistants.

Study Conditions

DEMA: Participants in the DEMA group received six bi-weekly personalized sessions with a trained intervener, two face-to-face and four via telephone (Appendix 5).[50] In order to inform personalization, PwMCIs and caregivers separately completed the Dementia Deficit Scale to gauge the PwMCI's level of awareness of functional ability[154] and the Canadian Occupational Performance Measure (COPM) to understand the types and frequencies of daily meaningful activities as well as barriers to engagement.[27,29,155] Principles of Problem-Solving Therapy (PST)[156,157] that were consistent with overall intervention goals were applied, providing autonomy support via facilitating PwMCI to identify and prioritize activities, categorize needs and goals,

contextualize manageable solutions, engage in self-selected activities with family support, and self-evaluate challenges and successes or renew problem-solving as indicated. PwMCI-caregiver dyads were encouraged to utilize the DEMA activity log, as well as the self-reported frequency and duration of activities that were then collected at follow-up (T3).

IS: The IS group received two face-to-face meetings to receive a study overview and an initial Alzheimer Association educational brochure. IS group members then received four bi-weekly follow-up phone calls where they benefited from opportunity to ask only education material-related questions.

Treatment Fidelity: The parent study employed treatment fidelity strategies that were based on National Institutes of Health (NIH) Treatment Fidelity Work Group[158] recommendations to ensure treatment integrity, mitigate experimental drift, and minimize contamination across groups. Strategies that were employed included: 1) Employment of standardized training and study manual for both DEMA and IS, and standardized measurement procedures; 2) checklists for quality assurance; 3) self- and external monitoring of audio-recorded DEMA, IS and measurement sessions; 4) intervener field notes each session to document dose (duration and frequency) as well as perception of study condition; 5) digital audio-recorders to detail DEMA and IS content, and duration; 6) separate intervener/evaluator conference meeting calls; 7) weekly study administration team meetings to address new or on-going concerns. Two interveners were trained to deliver both study conditions in order address risk associated with unmasking evaluators. A minimum of three quality assurance monitoring procedures were conducted for the first three dyad intervention or measurements for each intervener/evaluator to mitigate the risk

for experimental drift. Subsequently, 10% of interventions/evaluations were randomly reviewed by the quality assurance monitor.

Data Collection │ Instrumentation

This secondary data analysis focuses on a subset of outcome data collected at baseline, posttest (T2) and follow-up (T3). Instruments utilized include the Patient Health Questionnaire (PHQ-9),[63] the Notwotny Confidence Scale,[62] the Canadian Occupational Performance Measure (COPM) and the Alzheimer Disease Cooperative Study – Activities of Daily Living Inventory (ADCS-ADL).[64] Analysis of process outcomes addresses activity type, along with frequency and duration of primary and secondary meaningful activity. In the DEMA group, dyads used an "activity plan" and activity log as support tools designed to help them reach their stated goals. PwMCI recorded process data with caregiver support. Each session, the intervener worked with the DEMA dyad to review and evaluate activities in which they engaged between the bi-weekly sessions. Process data were collected at each of the six sessions.

The PHQ-9[63,159] is the depression module of the Patient Health Questionnaire (PHQ), which scores each of the 9 DSM-IV criteria as "0" (not at all) to "3"(nearly every day) (Appendix 3). Items are according to increased frequency of experiencing difficulties in each area covered. Scores are then summed, indicating severity of depressive symptoms as none (0-4), mild (5-9), moderate (10-14), moderate severe (15-19), and severe (20-27). This instrument demonstrates sufficient sensitivity when used to assess self-reported depressive symptoms in individuals with dementia.[160,161] The Notwotny Confidence Scale is a subscale of the Nowotny Hope Scale that uses a four-point Likert response format of strongly agree to strongly disagree to self-report of

confidence in one's own ability; content validity was established via literature review and expert panel (Appendix 2).[62,162,163]

The COPM [27,155] is an individualized, valid and reliable objective measure of a person's self-perceived experiences of occupational performance (interface between the person and environment) through measurement of a client's ratings of activity, satisfaction and performance as correlated to self-care, productivity and leisure (Appendix 1).[164] Clients identify their most important problems in occupational performance and provide a 0 to 10 score for both performance and satisfaction. Higher scores indicate greater activities performance and satisfaction. The tool is commonly used as a method of assessment for directing occupational therapy interventions and measuring client-centered outcomes by detecting change in a client's self-perception of occupational performance over time.[27,59]

The ADCS-ADL[64] is a twenty-four item instrument that assesses physical functional ability with everyday tasks on the basis of informant ratings of client performance. The interview may be completed in person or by telephone. The informant is directed to focus on the past four weeks and on what the patient actually did as opposed to estimating what the patient might be able to do (Appendix 4). The instrument is commonly used in clinical trials for AD.[165,166] Studies indicate that the items comprising the ADCS-ADL are sensitive to characteristic longitudinal trajectories in AD.[64,165,167] Quantitative outcome measures collected across time points and analyzed in this secondary analysis present with sufficient psychometric properties, sensitivity to change, and reasonable response burden (Table 3).

**Table 3.** Quantitative measures.

| Outcomes | Measures | Reliability | Administration Schedule | Completed By |
|---|---|---|---|---|
| Sense of confidence / mastery | Nowotny Confidence Scale | .83 to .92 | T1, T2, T3 | Patient |
| Meaningful activities engagement, performance & satisfaction | Canadian Occupational Performance Measure and weekly log | .86 to .95 | All sessions, T1, T2, T3 | Patient |
| Depressive Symptoms | PHQ-9 | .83 to .92 | T1, T2, T3 | Patient |
| Physical Function | ADCS-ADL | .91 | T1, T2, T3 | Patient |

Empirical phenomenology is useful to describe the commonality of a phenomenon across experiences. The qualitative data of this secondary data analysis was based on empirical phenomenology. Separate, open-ended phenomenological interviews were conducted with DEMA participants through telephone interviews after follow-up (T3) completion of outcome measures at three months post-program.

Data Management: A telephone log and participant calendar was utilized to track and schedule participant meetings. Study data was gathered on paper forms that was then entered into and managed using the REDcap system. Data was then exported from REDcap into a SAS-format data set and descriptive statistics were used to identify patterns of missing and outlying values. Patterns in question were cross-checked and confirmed using hard copy forms. The limited sample size precluded incorporation of missing data methods such as multiple imputations.

Secondary Analysis | Grant Identification: Secondary analysis was performed from the parent study involving PwMCI participating in the Indiana Alzheimer Disease Center (IADC) DEMA program: NIH Grant Number: 1R21 NR013755-01; project title: "Meaningful activity intervention for persons with mild cognitive impairment"; name of

grantee organization: Indiana University-Purdue University Indianapolis; project period start date: 07/01/2012; project period end date: 06/30/2015. Subsequent to participant feedback, preliminary and initial study findings,[47,49,50] the DEMA acronym was updated to represent Daily Engagement of Meaningful Activities and is referred to as such throughout the remainder of this dissertation.

Overall Hypothesis

Using phenomenological methodology, interviews were conducted at follow-up (T3) to elucidate PwMCIs' experience of engaging in the meaningful activity intervention. Broad, data-generating questions with relevant follow-up were employed to enhance insight into PwMCIs' perceived changes in confidence, activity performance, and physical function (Appendix 6). Rigorous qualitative analysis may reveal commonality of experiences that will then be used to inform design, replicability and scalability of future studies was well as translation to clinical practice.

Dyads (PwMCI and caregivers) who completed the DEMA program were measured at baseline, posttest (T2) and follow-up (T3) across all three domains of the ICF model. First, the inter-relationship of this model indicates potentially significant associations among confidence (personal factors), MCI stage (health condition), self-reported depressive symptoms (body functions/structure), and activity (ICF activity versus participation level). Second, change in confidence (personal factors), activity self-rated performance (activity) and physical function (activity), may predict change in depressive symptoms (body functions and structure). Third, change in confidence (personal factors) may predict change of activity self-rated performance (activity) and physical function (activity). Finally, exploration of data tendencies and evaluation of

potential difference within and between groups may demonstrate significant difference in activity frequency, duration, and engagement at the ICF participation level.

Qualitative Data Analysis | Rigor:

**Aim 1**: To describe PwMCI experience of engagement in the meaningful activity intervention as related to perceptions of changes in confidence, activity performance, and physical function. *Analysis*: Colaizzi Method of empirical phenomenology.

Secondary qualitative analysis adhered to Colaizzi's method (Table 4), a rigorous,

**Table 4**. Colaizzi's Method.

| | |
|---|---|
| **1.** | Familiarity with the experience as a whole through repeated audiotape and transcript review |
| **2.** | Multiple transcript readings: significant statements identified, restated, and formulated into meanings |
| **3.** | Formulated meanings reviewed and discussed with experienced research mentors until consensus reached |
| **4.** | Themes extracted from the formulated meanings |
| **5.** | Extracted themes were organized into a hierarchy of themes |
| **6.** | Theme clusters and categories examined and adjusted until consensus ensured |
| **7.** | Exhaustive narrative description of the experience that incorporated all themes elucidated |
| **8.** | Essential structure of the experience |

disciplined method commonly employed with empirical phenomenology.[51,53,54] Each interview was digitally audiotaped and labeled with numeric codes to ensure confidentiality, as well as accuracy of tracking group and time point. The audiotapes were then professionally transcribed and the de-identified, transcribed data was analyzed using a step-by-step procedure adapted from Colaizzi's phenomenological method.[168] First, familiarity with the experience as a whole was gained by listening to the taped interviews and reading transcriptions for exactitude. Second, multiple transcript readings were conducted whereby significant statements were identified, restated, and formulated into meanings by the first author (Table 5). Statements, restatements and formulated

meanings were assigned alpha-numeric codes to ensure accuracy and reproducibility of each analysis phase. Third, the formulated meanings were reviewed and discussed in meetings with experienced research mentors until consensus was reached. The primary author employed bracketing, the intentional act of acknowledging and setting aside one's biases, to most accurately convey participants' meanings throughout the process.[123] Fourth, themes were extracted from the formulated meanings. Analysis then proceeded to the arrangement of formulated restatements into theme clusters, which were then synthesized into emergent theme categories (Table 5).[53,54] Fifth, extracted themes were organized into a hierarchy of themes across all PwMCI data. Sixth, theme clusters and categories were examined and adjusted until consensus was reached during regular meetings with experienced research mentors. Serving as mentors for the secondary qualitative analysis were: (1) Yvonne Lu, PhD, RN, Associated Professor, Indiana University School of Nursing, Department of Science and Nursing Care; (2) Joan Haase, PhD, RN, FAAN; Halmquist Professor of Pediatric Oncology Nursing, Indiana University School of Nursing, Co-Director, The RESPECT Signature Center at IUPUI. After full agreement on theme categories was achieved, analysis proceeded to the seventh step. An exhaustive narrative description of the experience that incorporated all themes was elucidated. Finally, the essential structure of the experience was explicated.

**Table 5.** Example of Colaizzi's Method.

| Significant Statement | Restatement | Formulated Meaning | Theme Category |
|---|---|---|---|
| 07.17) some of my work activities, learning to break them down into smaller parts, and making lists, that has really helped me. | RS07.17) related to my work activities, learning to break them down into more manageable parts, and making lists, that has been a help to me | FM07.17) self-reminders and task segmentation supports on-going work capacity and function | Activity engagement fosters skill-building and functional preservation |
| 24.18) when I go in a store now I kind of line myself up with a sign or something on the building, and then I try to remember that when I come out, and that helps quite a bit as far as finding my car. | RS24.18) I take notice and line myself up with a sign or marker on the building and then make a conscious effort to remember that when I come back out, and helps quite a bit specific to finding my car. | FM 24.18) planning ahead and following a system are useful strategies to engage in activity outside home (participation) | DEMA promotes sense of mastery through practical strategies such as planning, problem-solving and teamwork |

In the example (Table 5) "07.17" refers to subject identification ("07) and the significant statement identifier (".17"). Such coding permitted systematic categorization and accuracy of reference during subsequent review and discussion. Careful employment of several strategies ensured validity, value, and credibility of the results. Prior to data collection, the interviewers conducted practice interviews and received peer critique to ensure a consistent approach to the interview process. Data analysis and validation were conducted as a team. For example, theme categories were derived separately by members of the research team then compared for consistency. The few incongruities were discussed in depth by the research team until one hundred percent agreement was achieved.

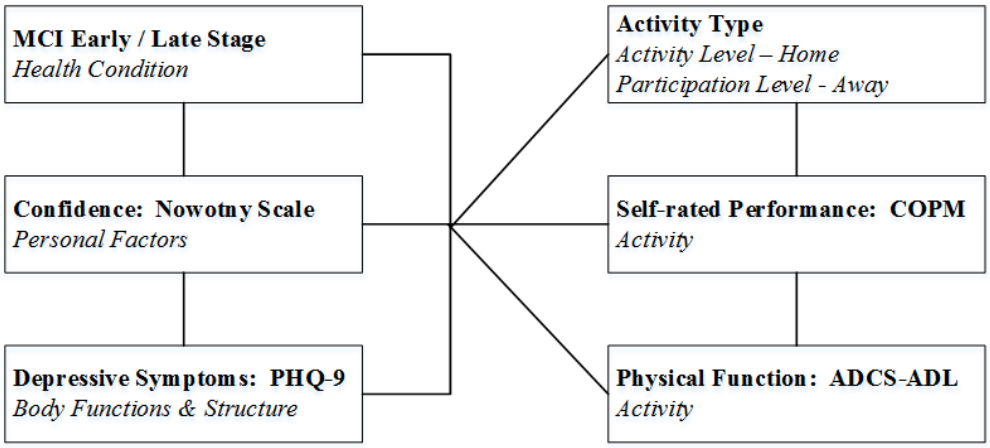
Quantitative Data Analysis:

Dyads (PwMCI and caregivers) who completed the DEMA program were measured at baseline, posttest (T2) and follow-up (T3) across all three domains of the ICF model. The inter-relationship of this model indicates a potentially significant relationship among confidence (personal factors), MCI stage (health condition), self-reported depressive symptoms (body functions/structure), and activity (ICF activity versus participation level). Additionally, change in confidence (personal factors), activity self-rated performance (activity) and physical function (activity), may predict change in depression (body functions and structure). Finally, change in confidence (personal factors) may predict change of activity self-rated performance (activity) and physical function (activity).

**Aim 2**: In the whole group (DEMA and IS) at baseline, evaluate relationships among MCI stage (early versus late), confidence (Nowotny Confidence Scale), self-reported depressive symptoms (PHQ-9), activity type (ICF activity or participation level), self-rated activity performance (COPM) and physical function (ADCS-ADL). *Analysis*: Pearson's Product Moment Correlation, Spearman's rho correlation.

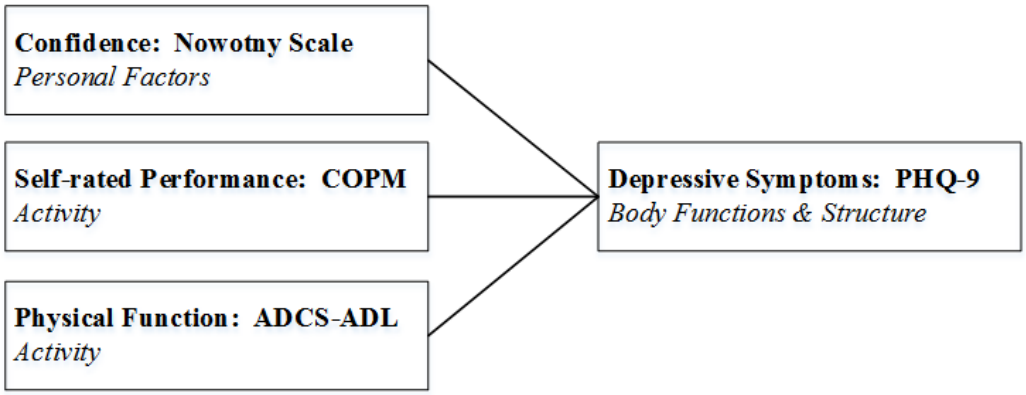
**Aim 3:** In the DEMA group, evaluate posttest (T2) relationships among MCI stage (early versus late), confidence (Nowotny Confidence Scale), self-reported depressive symptoms (PHQ-9), activity type (ICF activity or participation level), self-rated activity performance (COPM) and physical function (ADCS-ADL) (Figure 5). *Analysis*: Pearson's product moment correlation, Spearmans' rho correlation.

**Figure 5.** Hypothesized structural model of inter-related factors.




**Aim 4**: In the DEMA group, change (posttest and follow-up from baseline) in confidence (Nowotny Confidence Scale), activity self-rated performance (COPM), physical function (ADCS-ADL), predicts change of self-reported depressive symptoms (PHQ-9) (Figure 6). *Analysis*: Linear Regression.

**Figure 6.** Hypothesized predictability. Posttest and follow-up change from baseline.

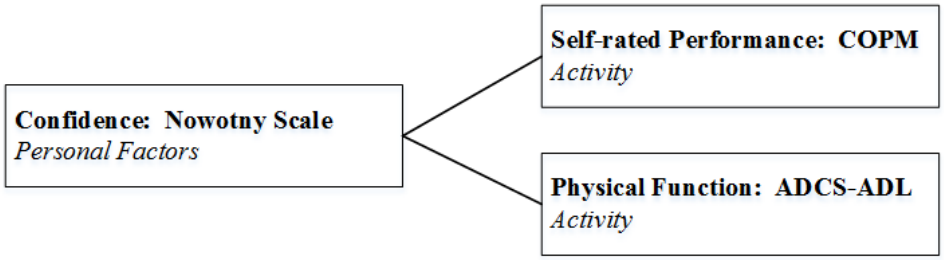



Hypothesis 4.1: Posttest from baseline change in confidence (Nowotny Confidence Scale), activity self-rated performance (COPM), physical function (ADCS-ADL), predicts change of self-reported depressive symptoms (PHQ-9). *Analysis*: Linear Regression.

Hypothesis 4.2: Follow-up from baseline change in confidence (Nowotny Confidence Scale), activity self-rated performance (COPM), physical function (ADCS-ADL), predicts change of self-reported depressive symptoms (PHQ-9). *Analysis*: Linear Regression.

**Aim 5**: In the DEMA group, change (posttest and follow-up from baseline) in confidence (Nowotny Confidence Scale) predicts change of activity self-rated performance (COPM) and change of physical function (ADS-ADL) (Figure 10).

**Figure 10.** Hypothesized predictability. Posttest and follow-up changes from baseline.




Hypothesis 5.1: Posttest from baseline change in confidence (Nowotny Confidence Scale) predicts change of activity self-rated performance (COPM).

*Analysis*: Linear Regression

Hypothesis 5.2: Follow-up from baseline change in confidence (Nowotny Confidence Scale) predicts change of activity self-rated performance (COPM). *Analysis*: Linear Regression.

Hypothesis 5.3: Posttest from baseline change in confidence (Nowotny Confidence Scale) predicts change of physical function (ADCS-ADL). *Analysis*: Linear Regression

Hypothesis 5.4: Follow-up from baseline change in confidence (Nowotny Confidence Scale) predicts change of physical function (ADCS-ADL). *Analysis*: Linear Regression.

Human Subjects Involvement and Characteristics: All recruitment procedures were reviewed and approved by the Indiana University Purdue University at Indianapolis Institutional Review Board (IRB) prior to initiation of the study. PwMCI caregiver dyads were volunteers and were identified by Dr. Farlow, Dr. Saykin, the faculty of the Indiana Alzheimer Disease Center (IADC) Clinical Core and Dr. Unverzagt from an existing NIA R0-1 funded study: "CIND: Risk factors for conversion to dementia." Initial invitation to participate was accompanied by a recruitment package that consisted of the pertinent study brochure, two copies of the authorization for the release of the health information for research forms, and two copies of informed consent. The brochures emphasized that study participation was entirely voluntary and decisions whether or not to participate would not in any manner impact care received. Potential participants were contacted by the research staff approximately one week following receipt of the study recruitment package. Research staff answered questions, determined degree of interest, screened for eligibility and provided informed consent for those who were eligible and interested in the study. All PwMCI and their caregivers were again reminded that study participation was entirely voluntary and that they were at liberty to withdraw from the study at any time.

Subjects' age, education, occupation, gender and self-reported ethnicity were recorded. All data were linked to subjects using a unique subject ID. A list of coded numbers identifying names, addresses and telephone numbers were retained in a locked file cabinet in the principle investigator's office. All study data were collected using confidential means through phone interviews by the research assistant in the research office. Collected materials were stored in locked file cabinets or secure rooms with

controlled access. After all relevant data were collected, the information was destroyed. All REDcap database and digital audio-recordings were housed in password protected files on IU School of Nursing's secure server. Access to the database or enrolled study participant / caregiver contact information was restricted to authorized study personnel. For a period of at least five years, all completed audio-recordings, transcriptions, data coding sheets, and computer files will be retained, at which time the list of subjects' names will be destroyed. Analysis and reporting of study results was restricted to reference as group data, no individual was or will be identified.

Mitigation of Risk: Recruitment of subjects followed a well-formulated plan approved by the IRB at Indiana University prior to study initiation. Potential risks during the study entailed exposure of confidential information, stress or fatigue from testing or intervention sessions, and disputes or misunderstandings between PwMCI and caregivers. Data collectors and interveners were trained to be watchful and perceptive to signs of risk and to take appropriate precautions, such as an offered break from the interview or intervention session, if such symptoms became evident. Additionally, flexibility existed to divide a single session into two sessions over two days if signs of fatigue or discomfort became apparent. In the unlikely instance that a PwMCI or caregiver demonstrated signs or symptoms of distress, she or he were encouraged to contact his or her primary physicians or were provided the contact number to the local Mental Health Clinic or Crisis Hotline. In the event that PHQ-9 depression scores were higher than 19, the same procedures were employed.[169]

In order to mitigate risks to confidentiality, case report forms and research documentation contained only a numeric subject ID [SUBID], not a name. A singular

table related the subject's name to the SUBID. The principle investigator retained that singular table in a locked file cabinet apart from the data collection forms. Physical risk was unlikely, with the alternative available to not participate or discontinue study participation. PwMCI or caregivers could withdraw at any time, or could choose not to answer items during intervention sessions or data collection interviews.

Benefits of research to human subject and others: Study subjects (PwMCI-caregiver dyads) received small stipends, a $40 gift card per dyad for completing each of the data collection sessions, equating to $120.00 total per dyad. Additionally, subjects in the DEMA group may have benefited from learning more about MCI and strategies for living with memory impairment as well as from individualized sessions and attention from the nurse intervener while building problem-solving skills while engaging in meaningful activities. Subjects in the IS group may have benefited from receiving information about local resources and reading educational brochures specific to MCI. Potential benefits outweighed the minimal risks associated with study participation such as fatigue, anxiety, or nominal risks of loss of confidentiality.

Specific to the DEMA group, 17 dyads completed posttest and 16 dyads completed follow-up data collection. Of the IS group, 18 dyads completed both posttest and follow-up (refer to Figure 8).

Following study completion and primary analysis of results specific to feasibility, acceptability and satisfaction, a secondary analysis of data was conducted. The following results address PwMCI lived experience of participation in the DEMA intervention, as well as hypothesized association, predictability, and difference. Pursuant to address of stated aims, process data tendencies were examined.

Chapter IV

Results

Qualitative Findings

**Aim 1**: To describe persons with mild cognitive impairment (PwMCI) experience of engagement in the meaningful activity intervention as related to perceptions of change in confidence, activity performance, and physical function. *Analysis*: Colaizzi Method of empirical phenomenology.

A total of 521 significant statements about the experience of participation in the DEMA program were extracted from the data and analyzed. Table six shows the twelve theme clusters that were identified, from which five theme categories emerged.

**Table 6.** Theme categories for experience of engagement in meaningful activities.

| | |
|---|---|
| **1** | **Refusing solitary confinement: engagement prompts shifting from exclusion & isolation to inclusion & interconnectedness** |
| | 1.1 DEMA program encourages awareness, openness and flexibility |
| | 1.2 Community and comradery promotes a sense of belonging, reciprocity and mutual benefit |
| | 1.3 Partnership and shared interest encourages on-going activity engagement |
| **2** | **Engagement entails making adjustments while optimizing degrees of being able** |
| | 2.1 Activity engagement fosters skill-building and functional preservation. |
| | 2.2 DEMA promotes a sense of mastery through practical strategies such as planning, problem-solving and teamwork. |
| | 2.3 Engagement in meaningful activities enhances one's sense of fulfillment and accomplishment |
| **3** | **Engagement is catalyzed by 'I think I can, I know we can'** |
| | 3.1 Teamwork promotes a sense of adaptability and buoyancy |
| | 3.2 Support is more than just physical assistance |
| **4** | **Working through & around by re-framing & reinvesting** |
| | 4.1 DEMA program sessions and tools reinforce focus on ownership, abilities and options-oriented approach |
| | 4.2 DEMA program deepens insight into performance and broadens perspective |
| **5** | **Perpetual activity engagement & reconciliation involves holding on while letting go** |
| | 5.1 Desiring continued involvement while realizing ever-increasing limitations |
| | 5.2 Preparing for the future involves reframing expectations, adjusting in the present, anticipating the worst but hoping for the best |

The following provides a detailed description of the themes related to each category. Select PwMCI Daily Engagement Meaningful Activity (DEMA) participant quotes exemplify the identified theme categories.

**Theme Category 1: Refusing solitary confinement – engagement prompts shifting from exclusion and isolation to inclusion and interconnectedness.**

Progressing through the DEMA program fostered increased awareness of functional and participation implications of memory changes. Awareness aided adjustment toward realistic expectations, increased openness and inclusion through multi-layered interactions, as well as affirmed personal identity and confidence to ask for and receive help.

Theme Cluster 1.1: DEMA program encourages awareness, openness and flexibility.

| |
|---|
| … as opposed as trying to go and do something and saying there's no help, just go ahead and get help period and be open to somebody helping me with the difficulty. [56.13-14] |
| My spouse has helped me…so that I'm not doing too much...my co-workers are very patient with me when I make a mistake and don't make me feel bad about it…my family, particularly my brother, listens to me when I'm having a tough time… [07.10] |
| … what to expect and what your family would start expecting and that there is help out there and you can get some help to help deal with … and help the family cope with it. [81.07] |

Participation in activities with others generated opportunities for discourse and exchange that reinforced a sense of mutuality and connectedness.

Theme Cluster 1.2: Community and comradery promotes a sense of belonging, reciprocity and mutual benefit.

| |
|---|
| …it's things I enjoy doing and so I do them and it's just a big circle…I like woodworking, I like computers and I like golf and I like my friends… [09.32] |
| I think everybody that (spouse) and I associate with have a part. … It takes a lot of people to help you...we do things together…they're just great people…. [12.17 & 44] |
| …we talk about various things...to me one of the best things a person can have is friends… [40.51] |

A distinct sense of reassurance and purpose accompanied regular engagement with others, as noted by participant comments in relation to activity with family and friends.

Theme Cluster 1.3: Partnership and shared interest encourages on-going activity engagement.

| |
|---|
| …my friends … golf partners who have showed an interest in wanting to play the game and then we would go out and play… [24.13] |
| I seek people who share the same interests and also share interests in the same activities…it's just that maybe there is a feeling of camaraderie. [40.49-50] |
| … we (daughter and I) just talk and laugh and have a good time and we're still working. …we're talking and laughing and talking about old times and things we've been through and things we're going through and stuff. [81.20-21] |

**Theme Category 2: Engagement entails making adjustments while optimizing degrees of being able.**

DEMA PwMCI participants described engagement as a continuous, unfolding process of adjusting to cognitive and functional changes while developing practical strategies such as planning, problem-solving and team work to foster skill-building and optimize degrees of being able.

Theme Cluster 2.1: Activity engagement fosters skill-building and functional preservation.

Program participants identified regular engagement in meaningful activities as a priority toward improved activity performance and physical function.

| |
|---|
| Every day…my speech therapy is what I try to do every morning … [01.18]. |
| As far as my exercise there's times in the morning I don't really want to do that but I say I've got to do that, and when I do that then I feel better. [01.34] |
| I have to do them on a regular basis… [40.38] |
| Well, the exercise is probably the top of my list. Just the process of going through daily activities, weekly activities, trying to be positive… knowing that it is going to help us have a better life. [03.52] |
| It (DEMA) allowed me to make some challenges for myself in terms of what I could do and it let me know there were techniques that I could use to overcome some of the difficulties that I've had [56.01] |
| As long as I keep doing them….I don't have to worry about going downhill all that much… [09.39] |
| (most helpful aspect of DEMA) …the process itself, where you sit down and you talk about what can you do on a daily basis to stay active,…We've had to make doctor appointments and things, but never like an activity schedule and review and help from people like you. [03.61] |
| …if you stay busy that makes you use your mind and if you use it you won't lose it you know, if you stay busy concentrating on what you're doing… [81.13] |

Engagement in meaningful activities provided a conduit to functional skill-building and involved more than one facet, such as cognitive and physical. PwMCI noted improved concentration and physical activity. Additionally, participants voiced a sense of mastery through expansion of practical strategies such as planning, problem-solving and team work.

Theme Cluster 2.2: DEMA promotes sense of mastery through practical strategies such as planning, problem-solving and teamwork.

| |
|---|
| …when I go in a store now I kind of line myself up with a sign or something on the building, and then I try to remember that when I come out, and that helps quite a bit as far as finding my car. [24.18] |
| I keep the date book that has everything, so I can remember what I'm doing each day, I check it each day...I write everything in there, I just keep it on hand. [73.11] |
| …some of my work activities, learning to break them down into smaller parts, and making lists, that has really helped me. [07.17] |
| …the laundry… I would go down in the basement and she would sort the clothes up there… and then I would go down and throw them in the washer. … then I would call her … and she would tell me how much detergent…bleach…fabric softener to put in, … and then what cycles to cycle the washer on. [24.20] |
| What I do now is write down where I am supposed to be, who I am supposed to meet, who I am supposed to call…I follow that particular calendar… [40.33] |

PwMCI program participants verbalized an enhanced sense of mastery/confidence through practical application of learned techniques that served to support on-going engagement efforts at both ICF activity and participation levels.

Regular engagement also appeared linked to a sense of fulfillment and accomplishment, where expanding preserved talents and abilities unique to one's individuality retained personal aptitude.

Theme Cluster 2.3: Engagement in meaningful activities enhances sense of fulfillment and accomplishment.

| |
|---|
| It is a good feeling when I go out and in particular with biking I do a lot of exploring and I go different places. For me that's not only both activities are exercise but they are also fun and neither of the activities are a chore. [40.35] |
| When you build something complicated and you stand back and look at it and think that you did a good job…there's probably nobody else in my neighborhood that could do them… I still think I do a good job on them… there's satisfaction and completion. [09.35-36] |
| … (activities) keep me busy, keep me focused instead of just sitting around and not doing anything. It keeps me stimulated. [81.15] |

> (Enjoy most about engaging in activities?) …the sense of accomplishment, meeting my goals. [07.18]

**Theme Category 3: Engagement is catalyzed by 'I think I can, I know we can'.**

Extending beyond personal capacity, PwMCI DEMA participants expressed greater degrees of perceived ability and flexibility linked to teamwork with their informal caregivers and extended support networks.

Theme Cluster 3.1: Teamwork promotes a sense of adaptability and buoyancy.

> …we will find a way to solve problems as they arise, and we have the ability to do that and we'll do it; we'll do what we need to do. [03.21]

> …I'm on the board for this community here…they help me and I help them...deciding on things…projects that they have to help get organized…whether I fix them or hire it done… [09.16-17]

> We just get it done every day… We have at it and she takes care of me and I take care of her. [69.38]

Informal caregiver partnering expanded confidence in one's ability to performed desired activities. Additionally, participants indicated that support was not limited to physical function assistance and could take on various forms.

Theme Cluster 3.2: Support is more than physical assistance.

> …she's the record keeper. We do a lot of things. We do a lot of things with our grandchildren and sports and education…. my wife and my kids see that I do the fun things that I want to do…. they see that I get everyplace. [12.19 & 46]

> (Spouse) can do that as far as that goes as well. She can drive that all over the place with no problem…we know exactly where we're going. [01.31]

> …If I get mired down in something she will ask 'are you going to go walk today?' She is just very supportive in anything and everything that I do… [40.77]

**Theme Category 4: Working through and around by re-framing and reinvesting**

Regardless of whether at the ICF activity or participation level, PwMCI DEMA participants identified improved capability to navigate challenges through reinforced focus on personal ownership, abilities and through employment of a variety of options to achieve on-going engagement.

Theme Cluster 4.1: DEMA program sessions and tools reinforce focus on ownership, abilities and option-oriented approach.

> It's up to me to decide when I'm going to do things and how to do them and everything like that. [90.29]

> …when I go scrapbooking, I have to decide what I'm going to work on and take my stuff with me. And when I do Bible study, I have a bag that has everything, my Bible that I take with me and paper, and all of those things are just in a bag and I grab it. I just know I have to be organized enough or else I'm not going to be prepared…. I have a system. [73.23]

> … (DEMA sessions help with)…coming up with different approaches, ways to approach the problem and solutions that come out of that… [03.30]

> (DEMA) helped focus…get me focused and doing things instead of sleeping in front of the television or something. So I think it helps keep you focused into place and keep going. [09.01]

> I've learned some new tools on how to work around my memory problems… making lists and breaking down the activity into smaller manageable pieces….and learning to say no and being realistic about what I am capable of doing… [07.05-.06]

PwMCI DEMA participants also verbalized enhanced insight into activity performance that paralleled broadening perspective.

Theme Cluster 4.2: "DEMA program deepens insight into performance and broadens perspective."

> I noticed is at the end of the day when I'm tired, that everything is more difficult for me…learn to just not tackle anything big at the end of the day… [07.19]

| |
|---|
| …it (DEMA) made me more aware of some of the difficulties I was having…I just recognize it more so than I did before that there are tools available for me and that I don't have to experience that difficulty, that level of difficulty. [56.05-08] |
| …the program has helped put things in perspective…Looking at situations, looking at potential problems, life in general. [40.02-03] |
| …opening up and feeling more confident and stronger… I tend to take more charge of the situation or an intervention than I did before. [56.16-17] |

**Theme Category 5: Perpetual activity engagement and reconciliation involves holding on while letting go.**

PwMCI voiced that engagement helped preserve a sense of personal identity and degrees of being able. Likewise, participants voiced awareness that changes in cognitive and physical function persisted as facets of on-going engagement. Participants related a sense of give-and-take, holding on while letting go, when discussing life themes, gauging personal abilities, and approaching decisions about the present and future.

Theme Cluster 5.1: Desiring continued involvement while realizing ever-increasing limitations.

| |
|---|
| …really enjoy it (lake house)… at this stage of the game for me… I cannot do this anymore with the lake house…it is the upkeep and just so many different things… [01.35] |
| … I was a physician way back when… things are different now, obviously,…I would like to try something else…maybe something else…would be better… [01.37] |
| … It just takes me a little longer to do (gardening) now than it used to. It used to I could go out there and whoop out a whole lot of stuff and now it takes me three or four hours to do a little job.… [81.20] |

DEMA program participants voiced concerns for the future and associated repercussions of cognitive and functional changes. In contrast to appraising personal

limitations, participants voiced that they possessed present-day capabilities to exercise judgment and formulate means to prepare.

Theme Cluster 5.2: Preparing for the future involves reframing expectations, adjusting in the present, anticipating the worst but hoping for the best.

| |
|---|
| …it's just a fear of what if things got really, really bad, …I want to live a long time,…but it is the thought that, is it going to get worse? Is there anything we can be doing to prepare for that? [03.45 & 55] |
| … I suppose old age, and what my life is going to be like… I'm just kind of concerned if something happens to my husband then I don't have any… I have very little family… [07.21] |
| Well, I'm constantly aware that if ... you hope that your deterioration is gradual and so far it's been that way, but sooner or later you just have to realize that you can't do everything you used to do. [12.31] |
| I don't really worry about it that much… I don't sit around and worry that I'm going to forget where I live or anything like that. It just isn't that far along yet, maybe someday. [24.25] |

Essential Structure

The lived experience of engagement in PwMCI who participated in the DEMA program involved a progressive awakening from self or other-imposed solitary confinement. DEMA program components supported a framework of alternatives and focus that reinforced one's personal sense of identity while shifting toward inclusion and interconnectedness. Participants voiced a process of adjusting to cognitive and functional changes while optimizing degrees of being able and articulated that DEMA sessions supported successive skill-building through use of practical strategies such as planning, problem-solving and team work. A sense of mastery, accomplishment and fulfillment expanded, whereby preserved talents and abilities enhanced one's sense of individuality and aptitude.

Informal caregiver, proximal and extended support networks enhanced PwMCIs' perceived ability to regularly perform desired activities. Moreover, support could take on various forms, indicating that support was not limited to merely physical or activities of daily living assistance. Driving was one example of such an activity where proximal and extended support dispelled isolation that is commonly associated with memory and functional changes.

DEMA participants expressed improved confidence to work through and around perceived barriers via reinforced focus on personal ownership, ability and identification of options. Participants articulated improved abilities to routinely navigate challenges and expand on-going activity engagement. Enhanced awareness and personal insight into activity performance paralleled broadening perspective, enabling PwMCI to contextualize performance and make decisions while remaining mindful of potential influencing factors.

Although future memory and functional changes remained persistent concerns, meaningful activity engagement involved embracing present opportunities and pro-active planning for the proximate future. Problem-solving and caregiver teamwork helped one hold on while letting go, as PwMCI identified and negotiated on-going changes. PwMCIs' increased awareness aided adjustment toward realistic expectations, increased openness and inclusion through multi-layered interactions, as well as affirmed personal identity and confidence to ask for and receive help.

Finally, PwMCI participants expressed perceived value of the DEMA program, as well as the need for program continuation.

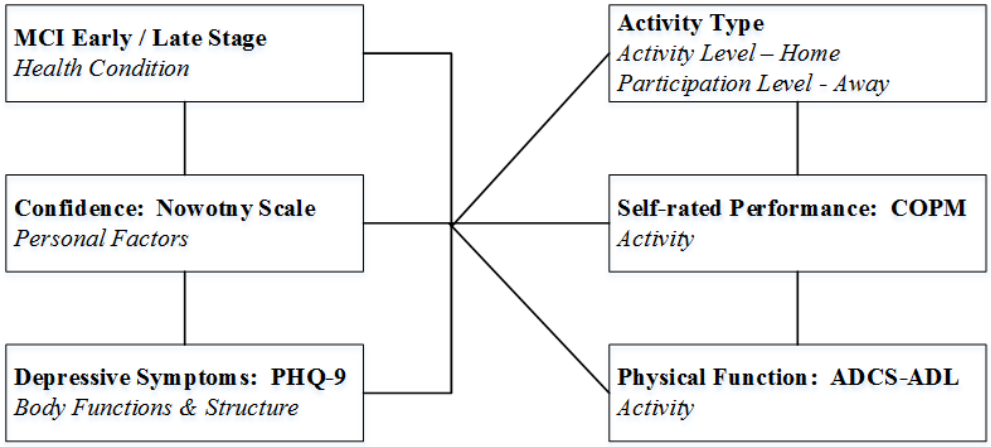
| |
|---|
| (DEMA) let me know that I'm not the only one,…and that there are things that you can do as a result to resolve some or make them not as big of a problem. [56.01] |
| A strong exercise program and using whatever means we have to or can use to battle this thing, where we need help…there are things out there and people out there who are going to… help us, and I'm all for your program and continuing it and improving it. [03.33] |
| You know a program like this is extremely important. If nobody pays any attention that means that there's no improvement, there's nothing. That's not been true. It's good to have these programs. [12.23] |

The experience of engagement in PwMCI who participated in the DEMA program may be likened to a rheostat switch. Opportunities to engage were self-identified and challenges were successfully navigated through structured, successive skill-building that illuminated activity alternatives while fostering confidence and improved self-perceived activity performance. Awareness and acknowledgement enlightened openness and flexibility to adjust to limitations while optimizing degrees of being able. Illumination and awakening were reinforced by caregivers, proximal and extended networks of support and an enhanced perception of interconnectedness.

Regardless of MCI stage or primary activity engagement by ICF level, PwMCI who participated in the DEMA program repeatedly expressed improved confidence and emotional affect. Moreover, they articulated detailed problem-solving principles that extended beyond the initial priority activity to successful engagement across a spectrum of secondary activities associated with successful performance of both life and societal roles. Qualitative findings clearly aligned with elements of the hypothesized model, as PwMCI voiced increased awareness and ability to engage in activities while adjusting to on-going changes, improved confidence and a sense of mastery with activities through planning, problem-solving and teamwork, and increased ownership of skill-building and

on-going engagement. The next logical step was to ascertain the extent of quantitative confirmation of PwMCI DEMA program participant experience (Figure 5).

**Figure 5.** Hypothesized structural model of inter-related factors.




Quantitative Findings

Data Analyses

Quantitative analyses were conducted using SAS 9.4 (SAS Institute Inc., Cary, North Carolina). PwMCI and caregiver demographic characteristics were summarized and then compared within and between the DEMA intervention and information support (IS) control groups. For this analysis, duration reports for PwMCI primary activity and secondary activities were calculated by multiplying frequency and duration. Calculation of percent change was achieved by working out the difference between the two values being compared, then dividing the difference value by the original number and multiplying the result by one hundred. Potential relationships among MCI stage (early versus late), confidence (Nowotny Confidence Scale), self-reported depressive symptoms (PHQ-9), activity type (International Classification of Functioning and Disability – ICF – activity or participation level), self-rated activity performance (Canadian Occupational Performance Measure, or COPM) and physical function (Alzheimer's Disease

Cooperative Study – Activities of Daily Living, or ADCS-ADL) were examined using Pearson product-moment and Spearman's rho correlation coefficients. Pearson's *r* correlation was used to test the relationship between variables in one sample comprised of interval data.[170,171] Spearman's rank correlation was used to test the relationship between variables in one sample comprised of ordinal and interval data.[170,171] Simple linear regression was repeatedly performed to assess the ability of change (posttest and follow-up from baseline) in confidence (Nowotny Confidence Scale), activity self-rated performance (COPM) and physical function (ADCS-ADL) to predict change in self-reported depressive symptoms (PHQ-9). Linear regression was again employed to assess the ability of change in confidence to predict change of activity self-rated performance and physical function. Examination of data tendencies employed descriptive statistics to ascertain primary and secondary activity duration, frequency of secondary activities at the ICF activity versus participation level and activity self-rated performance and satisfaction. The independent sample t-test was used to discover difference in secondary activities by ICF level.

Demographics

Demographic characteristics are summarized in Table 7. Regarding the whole sample of PwMCI, mean age was 71.6 years (DEMA: mean = 71.23, *SD* = 6.8; IS attention control:

**Table 7.** Demographic characteristics of study PwMCI and caregivers at baseline.

| | PwMCI | | | Caregiver | | |
|---|---|---|---|---|---|---|
| Group | **DEMA** N=20 | **IS** N=20 | **p value** | **DEMA** N=20 | **IS** N=20 | **p value** |
| Age | | | | | | |
| Mean (SD) | 71.23 (6.84) | 76.47 (7.05) | 0.022* | 65.26 (7.23) | 70.47 (11.95) | 0.105 |
| Gender N (%) | | | | | | |
| Male | 12 (60.00) | 11 (55.00) | | 5 (25.00) | 7 (35.00) | |
| Female | 8 (40.00) | 9 (45.00) | 0.749 | 15 (75.00) | 13 (65.00) | 0.490 |
| Race N (%) | | | | | | |
| Caucasian | 16 (80.00) | 19 (95.00) | | 14 (70.00) | 19 (95.00) | |
| African American | 4 (20.00) | 1 (5.00) | | 4 (20.00) | 1 (5.00) | |
| Asia | 0 | 0 | | 1 (5.00) | 0 | |
| More than 1 Race | 0 | 0 | 0.342 | 1 (5.00) | 0 | 0.107 |
| Education (Year) Mean (SD) | 16.8 (4.1) | 16.15 (3.91) | 0.609 | 15.40 (3.23) | 15.85 (2.60) | 0.631 |
| Employment N | | | | | | |
| Employed Full Time | 2 (10.00) | 1 (5.00) | | 3 (15.00) | 6 (30.00) | |
| Employed Part Time | 1 (5.00) | 1 (5.00) | | 2 (10.00) | 1 (5.00) | |
| Retired | 17 (85.00) | 18 (90.00) | | 13 (65.00) | 13 (65.00) | |
| Not Employed | 0 | 0 | >0.999 | 2 (10.00) | 0 | 0.448 |
| MCI Stage (n, %) | | | | | | |
| Early MCI | 8 (40.00) | 10 (50.00) | | NA | NA | NA |
| Late MCI | 12 (60.00) | 10 (50.00) | 0.525 | | | |
| PHQ-9 (≥ 5) N (%) | | | | | | |
| Yes | 7 (35.00) | 8 (42.10) | | 4 (20.00) | 8 (40.00) | |
| No | 13 (35.00) | 11 (57.90) | 0.648 | 16 (80.00) | 12 (60.00) | 0.168 |

* = $p \leq .05$: represents significant difference between DEMA and IS

mean = 76.5, *SD* = 7.1), approximately 60% male (57.5%), chiefly Caucasian (87.5%), retired (87.5%) and presented with a mean education 16.5 years (DEMA: mean = 16.8, *SD* = 4.1; IS attention control self-management tool kit: mean = 16.2, *SD* = 3.9). Most

PwMCI presented in late stage MCI (55.0%) and demonstrated a PHQ-9 less than five (60.0%). The sample of caregivers presented with a mean age of 68.7 (DEMA: mean = 65.5, *SD* = 7.1; IS attention control: mean = 70.8, *SD* = 10.0), 75% female, chiefly Caucasian (82.5%), retired (65%) and presented with a mean education of 15.7 years (DEMA: mean = 15.4, *SD* = 3.2; IS attention control: mean = 15.9, *SD* = 2.6). The majority of caregivers demonstrated a PHQ-9 less than five (70.0%). No significant difference was detected between groups, except that PwMCI in DEMA were statistically significantly younger than those in IS attention control (age = 71.23 for DEMA, age = 76.47 for IS attention control, p = .022).

Secondary Analysis

Descriptive data for all study variables at each time point are shown in Table 8.

**Table 8.** Descriptive data for all study variables at each time point.

| Group | Variable | **Baseline** Mean (SD) | **Posttest** (T2) Mean (SD) | **Follow-up** (T3) Mean (SD) |
|---|---|---|---|---|
| **IS** | Confidence | 24.95 (4.17) | 26.76 (3.87) | 26.05 (3.98) |
| N=20 | PHQ-9 | 4.50 (4.55) | 3.71 (3.69) | 2.47 (2.87) |
| | COPM | 7.50 (3.19) | 8.86 (1.03) | 8.68 (1.25) |
| | ADCS-ADL | 40.89 (8.91) | 34.79 (12.61) | 39.12 (8.94) |
| | Activity Type, N (%) | | | |
| | Activity Level | 7 (35.00 %) | 7 (46.67%) | 6 (31.58%) |
| | Participation Level | 13 (65.00%) | 8 (53.33%) | 13 (68.42%) |
| **DEMA** | Confidence | 27.20 (3.53) | 27.82 (3.03) | 27.19 (2.64) |
| N=20 | PHQ-9 | 3.75 (4.00) | 3.24 (3.83) | 2.65 (4.20) |
| | COPM | 8.25 (1.65) | 8.42 (1.73) | 8.07 (1.79) |
| | ADCS-ADL | 39.95 (7.25) | 41.53 (7.37) | 41.00 (7.23) |
| | Activity Type, N (%) | | | |
| | Activity Level | 11 (55.00%) | 5 (41.67%) | 11 (73.33%) |
| | Participation Level | 9 (45.00%) | 7 (58.33%) | 4 (26.67%) |

Aim one was addressed in the qualitative results section, while aims two through five are addressed below.

**Aim 2**: In the whole group (DEMA and IS) at baseline, evaluate relationships among MCI stage (early versus late), confidence (Nowotny Confidence Scale), self-reported depressive symptoms (PHQ-9), activity type (ICF activity or participation level), self-rated activity performance (COPM) and physical function (ADCS-ADL). *Analysis*: Pearson's correlation coefficient (Table 9) and Spearman's rho correlation (Table 10).

Pearson correlation coefficients among confidence, PHQ-9, COPM activity type, and ADCS-ADL are shown in Table 9. In the combined sample at baseline, confidence

**Table 9**. Baseline relationships among interval outcome measures.

| | | Prob > \|r\| under H0: Rho=0<br>p value | | | |
|---|---|---|---|---|---|
| **Group** | | **Confidence** | **PHQ-9** | **COPM** | **ADCS-ADL** |
| **Whole** (N = 40) | Confidence | 1.00 | -0.35<br>0.026* | -0.01<br>0.943 | -0.08<br>0.624 |
| | PHQ-9 | | 1.00 | -0.11<br>0.50 | -0.11<br>0.521 |
| | COPM | | | 1.00 | 0.22<br>0.190 |
| | ADCS-ADL | | | | 1.00 |
| **IS** (N = 20) | Confidence | 1.00 | -0.40<br>0.084 | -0.09<br>0.697 | 0.12<br>0.636 |
| | PHQ-9 | | 1.00 | -0.05<br>0.832 | -0.13<br>0.597 |
| | COPM | | | 1.00 | 0.22<br>0.366 |
| | ADCS-ADL | | | | 1.00 |
| **DEMA** (N = 20) | Confidence | 1.00 | -0.27<br>0.246 | 0.02<br>0.940 | -0.35<br>0.140 |
| | PHQ-9 | | 1.00 | -0.21<br>0.366 | -0.08<br>0.732 |
| | COPM | | | 1.00 | 0.27<br>0.259 |
| | ADCS-ADL | | | | 1.00 |

*Note*. *= $p \leq .05$

showed a moderately negative association with self-reported depressive symptoms (PHQ-9: $r = -0.35$, $p = 0.026$), indicating that participants who rated their confidence higher

were less depressed. In the IS group at baseline, confidence was negatively associated with depressive symptoms ($r$ = -0.40), but this association was moderate and was not statistically significant (p = 0.084).

Spearman's correlation coefficients between MCI stage, confidence, PHQ-9, COPM, ADCS-ADL and activity type are shown in Table 10. IS group PwMCI in the late stage demonstrated significantly moderate negative correlation with depressive symptoms (PHQ-9: $r$ = -0.51, p = 0.025), and physical function (ADCS-ADL: $r$ = -0.50, p = 0.028), indicating that IS PwMCI in late stage were more likely to present with fewer depressive symptoms and lower physical function than those in early stage. In the DEMA group, MCI late stage demonstrated a significantly moderate negative correlation with depressive symptoms (PHQ-9: $r$ = -0.44, p = 0.050), indicating that DEMA PwMCI in late stage were more likely to present with fewer depressive symptoms than those in MCI early stage. Similar to the IS group, DEMA PwMCI in late stage showed a negative correlation with physical function; however, this was not statistically significant ($r$ = -0.44, p = 0.059). Activity type demonstrated a significantly moderate negative correlation with depressive symptoms (PHQ-9: $r$ = -0.61, p = 0.005) and positive correlation with self-rated occupational performance (COPM: $r$ = 0.66, p = 0.002). Such findings indicate that those PwMCI in the DEMA group who selected the primary target activity at the International Classification of Functioning and Disability (ICF) activity level reported fewer depressive symptoms on the PHQ-9. Additionally, those who selected their primary target activity at the ICF activity level at baseline were more likely to rate higher occupational performance.

**Table 10**. Baseline relationships among MCI stage, confidence, PHQ-9, COPM, ADCS-ADL and primary Activity Type by ICF level.

Prob > |r| under H0: Rho=0
p value

| Group | | MCI Status | Confidence | PHQ-9 | COPM | ADCS-ADL | Activity Type |
|---|---|---|---|---|---|---|---|
| IS (N = 20) | MCI Stage** | 1.00000 | -0.06173<br>0.7960 | -0.49858<br>0.0252* | -0.25004<br>0.2877 | -0.50302<br>0.0281* | 0.10483<br>0.6601 |
| | Activity Type*** | 0.10483<br>0.6601 | -0.14790<br>0.5337 | 0.23840<br>0.3114 | -0.10297<br>0.6657 | -0.29038<br>0.2278 | 1.00000 |
| DEMA (N = 20) | MCI Stage** | 1.00000 | 0.15318<br>0.5191 | -0.44377<br>0.0500* | -0.04557<br>0.8487 | -0.44097<br>0.0588 | 0.28721<br>0.2195 |
| | Activity Type*** | 0.28721<br>0.2195 | 0.13309<br>0.5759 | -0.60644<br>0.0046* | 0.65517<br>0.0017* | 0.08714<br>0.7228 | 1.00000 |

*Note*. * = $p \leq .05$
**MCI Stage: 0.0 = Early, 1.0 = Late.
***Activity Type by ICF level: 0 = participation, 1.0 = activity.

After baseline examination of both groups, analysis proceeded to evaluate posttest relationships among the DEMA group.

**Aim 3:** In the DEMA group, evaluate posttest (T2) relationships among MCI stage (early versus late), confidence (Nowotny Confidence Scale), self-reported depressive symptoms (PHQ-9), activity type (ICF activity or participation level), self-rated activity performance (COPM) and physical function (ADCS-ADL). *Analysis*: Pearson's product moment correlation and Spearman's rho correlation.

Relationships among Nowotny Confidence, depressive symptoms (PHQ-9), occupational performance (COPM), and physical function (ADCS-ADL) were assessed

for the DEMA group at posttest were evaluated using the Pearson product moment correlation coefficient (Table 11). No significant associations were discovered.

**Table 11.** DEMA posttest relationships among interval outcome measures.

| | | Prob > \|r\| under H0: Rho=0 p value | | | |
|---|---|---|---|---|---|
| **DEMA** | | **Confidence** | **PHQ-9** | **COPM** | **ADCS-ADL** |
| (N = 17) | Confidence | 1.00 | -0.14<br>0.588 | 0.10<br>0.758 | -0.08<br>0.753 |
| | PHQ-9 | | 1.00 | -0.38<br>0.226 | 0.26<br>0.320 |
| | COPM | | | 1.00 | 0.11<br>0.725 |
| | ADCS-ADL | | | | 1.00 |

Posttest DEMA Spearman's correlation coefficients between MCI stage, confidence, PHQ-9, COPM, ADCS-ADL and activity type are shown in Table 12. Data demonstrated a significantly moderate negative correlation between MCI late stage and ADCS-ADL ($r$ = -0.590, p = 0.013), indicating that those in late stage presented with lower physical function.

**Table 12**. DEMA posttest relationships among MCI stage, confidence, PHQ-9, COPM, ADCS-ADL and primary Activity Type by ICF level.

| | | Prob > \|r\| under H0: Rho=0 p value | | | | | |
|---|---|---|---|---|---|---|---|
| **Group** | | **MCI Status** | **Confidence** | **PHQ-9** | **COPM** | **ADCS-ADL** | **Activity Type** |
| DEMA (N = 17) | MCI Stage** | 1.00000 | -0.14868<br>0.5690 | -0.27379<br>0.2876 | 0.17555<br>0.5853 | -0.58989<br>0.0127* | -0.16903<br>0.5995 |
| | Activity Type*** | -0.16903<br>0.5995 | -0.07423<br>0.8187 | -0.22349<br>0.4850 | -0.17804<br>0.5799 | -0.02470<br>0.9393 | 1.00000 |

*Note*. * = p ≤ .05
**MCI Stage: 0.0 = Early, 1.0 = Late.
***Activity Type by ICF level: 0 = participation, 1.0 = activity.

Following examination of the data particular to aims two and three, further investigation was conducted on selected outcome measures to evaluate predictability of change in depressive symptoms. After sub-grouping the data and focusing on the DEMA group, the number of participant observations at posttest and follow-up was limited to sixteen, rendering multiple regression unrealistic due to limited statistical power. Consequently, separate linear regressions were run to evaluate potential predictability among the change scores of each identified variable on change in depressive symptoms.

**Aim 4**: In the DEMA group, change (posttest and follow-up from baseline) in confidence (Nowotny Confidence Scale), activity self-rated occupational performance (COPM), physical function (ADCS-ADL), predicts change of self-reported depressive symptoms (PHQ-9). *Analysis*: Linear regression.

Hypothesis 4.1: Posttest from baseline change in physical in confidence (Nowotny Confidence Scale), activity self-rated performance (COPM), and physical function (ADCS-ADL), predicts change of self-reported depressive symptoms (PHQ-9). *Analysis*: Linear Regression.

Summary of posttest linear regression results are shown in Table 13. Based on change in each predictor variable (confidence, COPM or ADCS-ADL), linear regression was calculated to predict change in depressive symptoms. The t-values were test statistics required for each parameter whereby p-values were calculated. Data demonstrated that change in activity self-rated occupational performance (COPM: $p = 0.0309$) statistically significantly predicted change in self-reported depressive symptoms (PHQ-9).

**Table 13**. Posttest (T2) DEMA change in confidence, COPM, ADCS-ADL prediction of change in depressive symptoms.

| Time | Effect | Estimate | Standard Error | DF | t value | p value |
|---|---|---|---|---|---|---|
| **Posttest** | **Intercept** | -0.1949 | 0.8568 | 15 | -0.23 | 0.8231 |
| (N = 17) | **Change of Confidence** | 0.08753 | 0.1978 | 15 | 0.44 | 0.6644 |
| | **Intercept** | 0.1718 | 0.7314 | 10 | 0.23 | 0.8190 |
| | **Change of COPM** | -1.3877 | 0.5529 | 10 | -2.51 | 0.0309* |
| | **Intercept** | -0.07671 | 0.9080 | 14 | -0.08 | 0.9339 |
| | **Change of ADCS-ADL** | 0.06438 | 0.1878 | 14 | 0.34 | 0.7368 |

*Note*. *= $p \leq .05$

Hypothesis 4.2: Follow-up from baseline change in confidence (Nowotny Confidence Scale), activity self-rated performance (COPM), physical function (ADCS-ADL), predicts change of self-reported depressive symptoms (PHQ-9). *Analysis*: Linear Regression.

Upon examining follow-up (T3) from baseline (Table 14) in the DEMA group, change in confidence (Nowotny Confidence Scale), activity self-rated performance (COPM), or physical function (ADCS-ADL) did not significantly predict change in self-reported depressive symptoms (PHQ-9). Although, change in confidence fell just short of statistical significance ($p = 0.0579$).

**Table 14**. Follow-up (T3) from baseline DEMA change in confidence, COPM, ADCS-ADL prediction of change in depressive symptoms.

| Time | Effect | Estimate | Standard Error | DF | t value | p value |
|---|---|---|---|---|---|---|
| **Follow-Up** | **Intercept** | -1.5191 | 0.7172 | 14 | -2.12 | 0.0525 |
| (N = 16) | **Change of Confidence** | -0.5867 | 0.2841 | 14 | -2.07 | 0.0579 |
| | **Intercept** | -1.5191 | 0.8112 | 13 | -1.87 | 0.0838 |
| | **Change of COPM** | -0.07865 | 0.3867 | 13 | -0.20 | 0.8420 |
| | **Intercept** | -2.2490 | 0.8417 | 13 | -2.67 | 0.0192 |
| | **Change of ADCS-ADL** | -0.2152 | 0.1718 | 13 | -1.25 | 0.2324 |

Following examination of ability of change in confidence, occupational performance and physical function to predict change in depressive symptoms, the data were examined to ascertain the ability of change in confidence to predict change of self-rated performance and physical function.

**Aim 5**: In the DEMA group, change (posttest and follow-up from baseline) in confidence (Nowotny Confidence Scale) predicts change of activity self-rated performance (COPM) and change of physical function (ADS-ADL).

Hypothesis 5.1: Posttest from baseline change in confidence (Nowotny Confidence Scale) predicts change of activity self-rated performance (COPM) (Table 15). *Analysis*: Linear Regression.

**Table 15.** DEMA posttest from baseline change confidence prediction of change in self-rated occupational performance (COPM).

| Change COPM | Effect | Estimate | Standard Error | DF | t value | p value |
|---|---|---|---|---|---|---|
| | Intercept | -0.2208 | 0.3841 | 10 | -0.57 | 0.5781 |
| | Change Confidence | -0.1237 | 0.08432 | 10 | -1.47 | 0.1731 |

Hypothesis 5.2: Follow-up from baseline change in confidence (Nowotny Confidence Scale) predicts change of activity self-rated performance (COPM) (Table 16). *Analysis*: Linear Regression.

**Table 16.** DEMA follow-up from baseline change confidence prediction of change in self-rated occupational performance (COPM).

| Change COPM | Effect | Estimate | Standard Error | DF | t value | p value |
|---|---|---|---|---|---|---|
| | Intercept | -0.6698 | 0.5607 | 13 | -1.19 | 0.2536 |
| | Change Confidence | 0.006821 | 0.2161 | 13 | 0.03 | 0.9753 |

Hypothesis 5.3: Posttest from baseline change in confidence (Nowotny Confidence Scale) predicts change of physical function (ADCS-ADL) (Table 17). *Analysis*: Linear Regression.

**Table 17.** DEMA posttest from baseline change confidence prediction of change in physical function (ADCS-ADL).

| Change ADCS-ADL | Effect | Estimate | Standard Error | DF | t value | p value |
|---|---|---|---|---|---|---|
| | Intercept | -0.9697 | 1.3304 | 14 | -0.73 | 0.4781 |
| | Change Confidence | 0.1674 | 0.3163 | 14 | 0.53 | 0.6050 |

Hypothesis 5.4: Follow-up from baseline change in confidence (Nowotny Confidence Scale) predicts change of physical function (ADCS-ADL) (Table 18). *Analysis*: Linear Regression.

**Table 18.** DEMA follow-up from baseline change in confidence prediction of change in physical function (ADCS-ADL).

| Change ADCS-ADL | Effect | Estimate | Standard Error | DF | t value | p value |
|---|---|---|---|---|---|---|
| | Intercept | -1.6686 | 1.3256 | 13 | -1.26 | 0.2303 |
| | Change Confidence | 0.3029 | 0.5186 | 13 | 0.58 | 0.5692 |

In the DEMA group, the data did not demonstrate significance specific to the ability of change (posttest and follow-up from baseline) in confidence (Nowotny Confidence Scale) to predict change of activity self-rated performance (COPM) or physical function (ADS-ADL). Baseline analyses indicated a statistically significant negative correlation between confidence and depressive symptoms in the combined group, as well as negative correlation between MCI late stage and depressive symptoms, as well as late stage and physical function in the IS group. Baseline DEMA findings indicated negative correlation between MCI late stage and depressive symptoms as well as activity type at the ICF activity level and depressive symptoms, while a positive correlation was noted between ICF activity level and self-rated occupational performance. DEMA posttest analyses indicated a negative correlation between MCI late stage and physical function. Analyses related to aim four DEMA group posttest indicated that change in self-rated occupational performance predicted change in depressive symptoms. Though follow-up analysis related to aim four, as well as posttest and follow-up analyses related to aim five

did not reveal statistically significant ability of other select variables to predict change, mean values indicated the potential to identify difference.

Primary Activity at ICF Participation Level – Confidence and Depressive Symptoms

Whole group baseline findings indicated a negative correlation between confidence and depressive symptoms while the DEMA group demonstrated a negative correlation between primary target activity by ICF activity level and depressive symptoms. Qualitative findings revealed that DEMA participants expressed a growing sense of mastery regardless of ICF level of engagement. The question then arose as to whether or not there was a difference in depressive symptoms or confidence when the primary target activity was sub-grouped by ICF level of activity or participation. Consequently, another aim was added to test for anticipated baseline difference and difference in change at posttest and follow-up.

**Aim 6:** Evaluate for difference in confidence and depressive symptoms by sub-grouped initial, primary activity at ICF level of activity or participation.

Hypothesis 6.1: In the DEMA group at baseline and posttest, evaluate difference in confidence (Nowotny Confidence Scale) and depressive symptoms (PHQ-9) between sub-grouped target primary activity at ICF activity or participation level. *Analysis*: Independent t-test.

DEMA participants were allocated to either an activity focused or participation focused subgrouping based upon ICF distinctions. Exploration of difference among confidence and self-reported depressive symptoms was conducted using the independent two sample t-test. Classification of activity level was based upon the first primary

reported activity. Results appear in Table 19. Significant baseline difference was found for depressive symptoms. PwMCI who self-reported more depressive symptoms on the PHQ-9 were more likely to initially select a primary activity at the ICF participation level ($p = 0.008$).

**Table 19**. DEMA baseline and posttest difference in confidence and depressive symptoms when target primary activity sub-grouped by ICF level of activity or participation.

| Time | N | Outcome | Activity Mean (SD) | Participation Mean (SD) | p value |
|---|---|---|---|---|---|
| **Baseline** | 11 = Activity | Confidence | 27.55 (3.86) | 26.78 (3.27) | 0.642 |
| | 9 = Participation | PHQ-9 | 1.73 (2.80) | 6.22 (3.96) | 0.008* |
| **Posttest** | 7 = Activity | Confidence | 28.20 (2.77) | 28.57 (3.55) | 0.850 |
| | 8 = Participation | PHQ-9 | 2.80 (3.35) | 4.71 (4.89) | 0.469 |

Note. *= $p \leq .05$

Hypothesis 6.2: In the DEMA and IS group, evaluate for posttest and follow-up from baseline difference in confidence (Nowotny Confidence Scale) and depressive symptoms (PHQ-9) at the ICF participation level. *Analysis*: Dependent t-test.

In DEMA and IS participants who were allocated to the ICF participation focused subgrouping, data were assessed for difference in confidence and depressive symptoms at posttest and follow-up from baseline using the dependent sample t-test. This was conducted separately for the DEMA and IS group. Posttest results for confidence are illustrated in Table 20. The DEMA group demonstrated a statistically significant difference in confidence at the ICF participation level. Although not significant, the IS group posttest results showed a mean decrease in confidence.

**Table 20.** Difference in confidence – posttest from baseline at ICF participation level, DEMA and IS.

| Group | N | Baseline Mean (SD) | Posttest Mean (SD) | Mean Difference | DF | Standard Error | t value | p value |
|---|---|---|---|---|---|---|---|---|
| DEMA | 7 | 26.55 (1.22) | 28.36 (0.83) | -1.8067 | 12 | 0.5613 | -3.22 | 0.0074* |
| IS | 8 | 25.52 (1.23) | 24.95 (1.23) | 0.5716 | 15 | 1.9495 | 0.29 | 0.7734 |

*Note*. *= $p \leq .05$

Analysis then progressed to examine potential difference at follow-up from baseline. Follow-up results for confidence appear in Table 21. The DEMA model could not be analyzed due to a limited number of subjects and change in IS data was not statistically significant.

**Table 21.** Difference in confidence – follow-up from baseline at ICF participation level, DEMA and IS.

| Group | N | Baseline Mean (SD) | Follow-up Mean (SD) | Mean Difference | DF | Standard Error | t value | p value |
|---|---|---|---|---|---|---|---|---|
| DEMA | 4 | NA | NA | NA | NA | NA | NA | NA |
| IS | 13 | 24.89 (1.12) | 25.96 (1.38) | -1.0787 | 16 | 1.0180 | -1.06 | 0.3050 |

Examination proceeded to test for difference in self-reported depressive symptoms. Results for depressive symptoms (Table 22), indicated that the DEMA PHQ-9 mean score decreased by 1.86 points while the IS mean score increased by 0.26. Although neither change was statistically significant, the DEMA group mean posttest score demonstrated a categorical shift ($\geq 5$ = mildly depressed).

**Table 22.** Depressive Symptoms – posttest from baseline ICF participation level, DEMA and IS

| Group | N | Baseline Mean (SD) | Posttest Mean (SD) | Mean Difference | DF | Standard Error | t value | p value |
|---|---|---|---|---|---|---|---|---|
| DEMA | 17 | 6.32 (1.25) | 4.46 (1.85) | 1.8539 | 12 | 2.5308 | 0.73 | 0.4779 |
| IS | 16 | 3.62 (0.84) | 3.88 (1.33) | -0.2551 | 15 | 1.0042 | -0.25 | 0.8029 |

Follow-up results for depressive symptoms are illustrated in Table 23. The DEMA group remained in the "no depression" category on the PHQ-9 (< 5) at follow-up. However, the findings were not statistically significant.

**Table 23.** Depressive Symptoms – follow-up from baseline ICF participation level, DEMA and IS.

| Group | N | Baseline Mean (SD) | Follow-up Mean (SD) | Mean Difference | DF | Standard Error | t value | p value |
|---|---|---|---|---|---|---|---|---|
| DEMA | 17 | 6.08 (1.31) | 1.77 (1.75) | 4.3046 | 11 | 2.1461 | 2.01 | 0.0701 |
| IS | 18 | 3.40 (0.82) | 2.67 (0.68) | 0.7343 | 16 | 0.7810 | 0.94 | 0.3611 |

Examination for difference was repeated at the ICF activity level for both groups. Posttest IS models for confidence and depressive symptoms could not be run due to limited sample size and a convergence issue. Neither the IS nor DEMA group data yielded significant findings at follow-up.

Aim six results demonstrated a significant DEMA posttest difference in confidence when the primary target activity engagement occurred at the ICF participation level. The relevant impact shift of confidence in response to engagement at the ICF participation level prompted additional consideration of how to better objectify impact of engagement on physical function at the ICF participation level. The ADCS-ADL is comprised of twenty-four questions purposed to assess a composite of activities of daily living and instrumental activities of daily living. In-depth review of the instrument

revealed a subset of questions at the ICF participation level. Examination of a composite sub-score would help objectify the impact of engagement on physical function at the ICF participation level. After identifying the question subset (Table 24), a composite sub-score was calculated with a sub-score total of seven possible points.

**Table 24.** ADCS-ADL ICF participation level questions.

| Question # | Possible Points | Question |
|---|---|---|
| 8 | 3 | In the past 4 weeks, did (Subject's Name) keep appointments or meetings with other people, such as relatives, a doctor, the hairdresser, etc.? |
| 11 | 3 | In the past 4 weeks, did (Subject's Name) get around (or travel) outside of his/her home? |
| 15 | 1 | In the past 4 weeks, did (Subject's Name) ever go shopping at a store? |

The ADCS-ADL sub-score, comprised of questions that represented function at the ICF participation level, was then assessed for difference posttest from baseline. The DEMA group (Table 25) demonstrated a statistically significant improvement in ICF participation level sub-score (posttest mean difference = 0.1500, p-value = 0.0430), while the IS group demonstrated a sub-score decrease. Additionally, findings demonstrated a significant difference in sub-score change between the DEMA and IS groups (T2 Change = 0.2127, p-value = 0.0436).

**Table 25.** ADCS-ADL sub-score change posttest from baseline DEMA and IS.

| Time Point | N | Mean (SD) | Mean Difference | Standard Error | t value | p value | Alpha | Lower | Upper |
|---|---|---|---|---|---|---|---|---|---|
| IS Change | 18 | 2.94 (0.25) | -0.0626 | 0.07242 | -0.87 | 0.3923 | 0.05 | -0.2093 | 0.08395 |
| DEMA Change | 16 | 3.00 (0.00) | 0.1500 | 0.07165 | 2.09 | 0.0430* | 0.05 | 0.004948 | 0.2951 |
| DEMA versus IS Change | | | 0.2127 | 0.1019 | 2.09 | 0.0436* | 0.05 | 0.006423 | 0.4189 |

*Note*. *= $p \leq .05$

The data did not demonstrate continuance of significant difference through follow-up (T3), as noted in Table 26.

**Table 26.** ADCS-ADL sub-score change follow-up from baseline DEMA and IS.

| Time Point | N | Mean (SD) | Mean Difference | Standard Error | t value | p value | Alpha | Lower | Upper |
|---|---|---|---|---|---|---|---|---|---|
| IS Change | 18 | 2.94 (0.24) | -0.05556 | 0.09390 | -0.59 | 0.5576 | 0.05 | -0.2457 | 0.1345 |
| DEMA Change | 16 | 2.88 (0.33) | 0.03667 | 0.09530 | 0.38 | 0.7026 | 0.05 | -0.1563 | 0.2296 |
| DEMA versus IS | | | 0.09222 | 0.1338 | 0.69 | 0.4948 | 0.05 | -0.1786 | 0.3631 |

Findings indicated that those in the DEMA group who selected their initial primary target activity at the ICF activity level were more likely to rate occupational performance higher at baseline. Posttest analysis demonstrated a significant difference in physical function at the ICF participation level sub-composite score. Additionally, it seemed prudent to gain additional insight into factors that may have influenced participant response to intervention. In light of the aforementioned, the decision was made to further examine process outcomes by looking at data tendencies of both primary target and secondary activity engagement. The decision to examine duration and

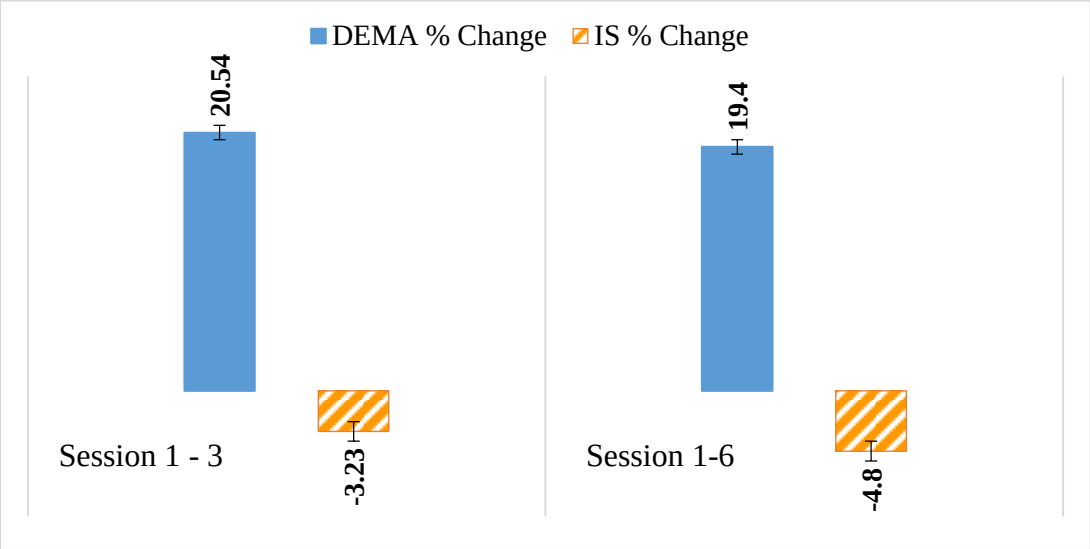
frequency was further validated by findings that DEMA participant data at the ICF participation level demonstrated a significant difference at posttest for change in confidence, as well as a clinically significant a categorical shift to the "not depressed" category of the PHQ-9. Could such differences be influenced by higher amounts of activity engagement when participants engaged at the ICF participation level? Of particular interest was total activity duration and frequency of engagement between sessions. Examination of primary target self-selected activity focused on total duration and frequency tendencies when sub-group by ICF level, as well as self-rated performance and satisfaction. Examination of secondary activities focused on total duration and frequency as sub-grouped by ICF level of activity or participation.

Data Tendencies

Primary Activity Duration

Further exploration of the data was performed to evaluate self-dosing (e.g.: duration, frequency) of activity. Initial examination focused on each group's percent change of target primary activity mean duration. Computation of mean duration, followed by calculation and comparison of DEMA versus IS percent change from session one to three and one to six was conducted. Percent change was ascertained by calculating the difference between the two means being compared, then dividing the increase by the original number and multiplying by one-hundred ($session_{(x)} - session_{(1)}/session_{(1)}$). The IS group demonstrated an overall decrease in target primary meaningful activity while the DEMA group demonstrated an overall increase, culminating in a 19.4% increase from session one to six (Figure 14).

**Figure 14.** DEMA vs. IS mean % change of target primary activity mean duration between session 1 to 3 and 1 to 6.




Tendencies for percent change of mean DEMA primary target activity duration were compelling. In order to better understand the consistency at which DEMA versus IS participants engaged; the decision was made to examine tendencies of primary target and secondary activity engagement.

Primary Activity Frequency

To better understand the influence of the DEMA intervention on primary self-selected activity frequency, group means for reported engagement between the bi-weekly sessions were compared. Comparison of DEMA and IS mean primary self-selected activity frequency as reported by session (Table 27) demonstrated a steady DEMA group increase in the mean number of times per week PwMCI participants engaged in activities across both ICF levels. From session one to six, the DEMA group demonstrated a steady increase from 3.42 to 5.13 primary activity frequency per week, demonstrating a 50% mean increase in activity frequency compared to decreased activity frequency of the IS group (-38.25%).

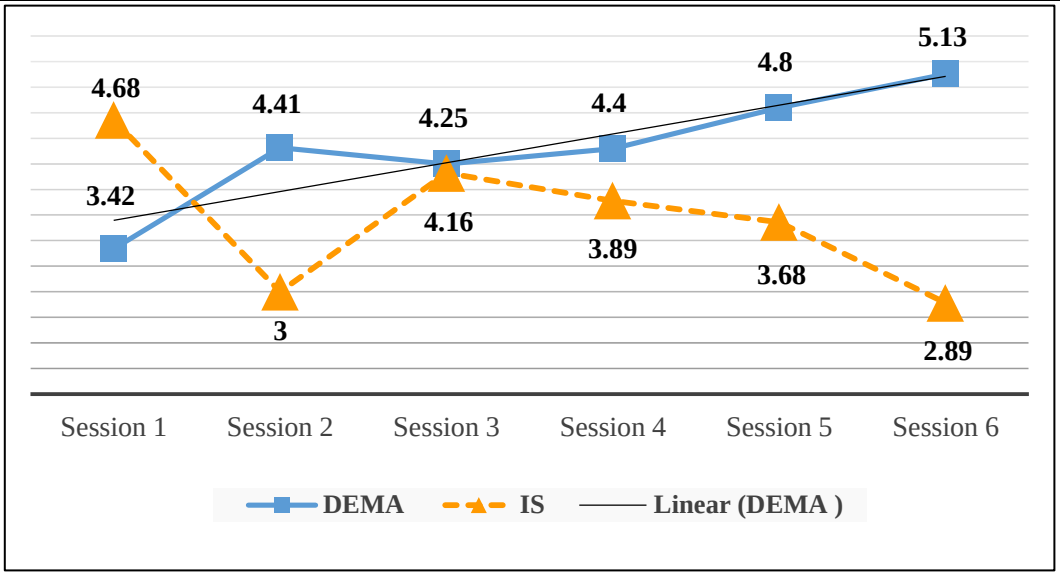
**Table 27**. DEMA vs. IS group mean target primary activity frequency reported each session.

| Session # | DEMA Frequency* N=17 | IS Frequency* N=19 |
|---|---|---|
| 1 | 3.42 (2.50) | 4.68 (2.58) |
| 2 | 4.41 (2.03) | 3.00 (2.28) |
| 3 | 4.25 (2.08) | 4.16 (2.69) |
| 4 | 4.40 (1.88) | 3.89 (2.73) |
| 5 | 4.80 (2.04) | 3.68 (2.60) |
| 6 | 5.13 (2.23) | 2.89 (1.94) |
| 1 versus 6 % change | 50% ↑ | 38% ↓ |

*Frequency = number of times engaged in target primary activity per week

Notable for both groups (Figure 15), session three appeared as a pivot-point, distinguishing each group's frequency trajectories across the remaining sessions.

**Figure 15.** Mean target primary activity frequency per week in DEMA vs.IS group.




After noting steady increase in DEMA group primary activity frequency from session one to six, the data were analyzed to discern whether cumulative duration influenced primary activity selection as reported at posttest (T2).

Primary Activity Type Duration by ICF Level

For the DEMA and IS group, data were analyzed to ascertain whether cumulative duration from session one to six predicted posttest (T2) primary activity type at the ICF activity or participation level (Tables 28-29). Two independent sample t-tests were employed to compare mean cumulative duration between ICF activity versus participation level. Equality of variances between the two groups was satisfied and the pooled method was taken into account. No significant difference was found for DEMA or IS group cumulative duration between primary target activity selection at the ICF activity versus participation level.

**Table 28.** DEMA target primary activity mean duration at ICF level of activity or participation.

| ICF Level | N | Mean (SD) | Std Err | DF | t value | p value |
|---|---|---|---|---|---|---|
| Activity Level | 5 | 485.4 (279.5) | 125.0 | 10 | -0.29 | 0.7773 |
| Participation Level | 7 | 547.9 (415.3) | 157.0 | 9.994 | -0.31 | 0.7620 |
| Diff (1-2) | | -62.4571 (367.0) | 214.9 | | | |

**Table 29.** IS target primary activity mean duration at ICF level of activity or participation.

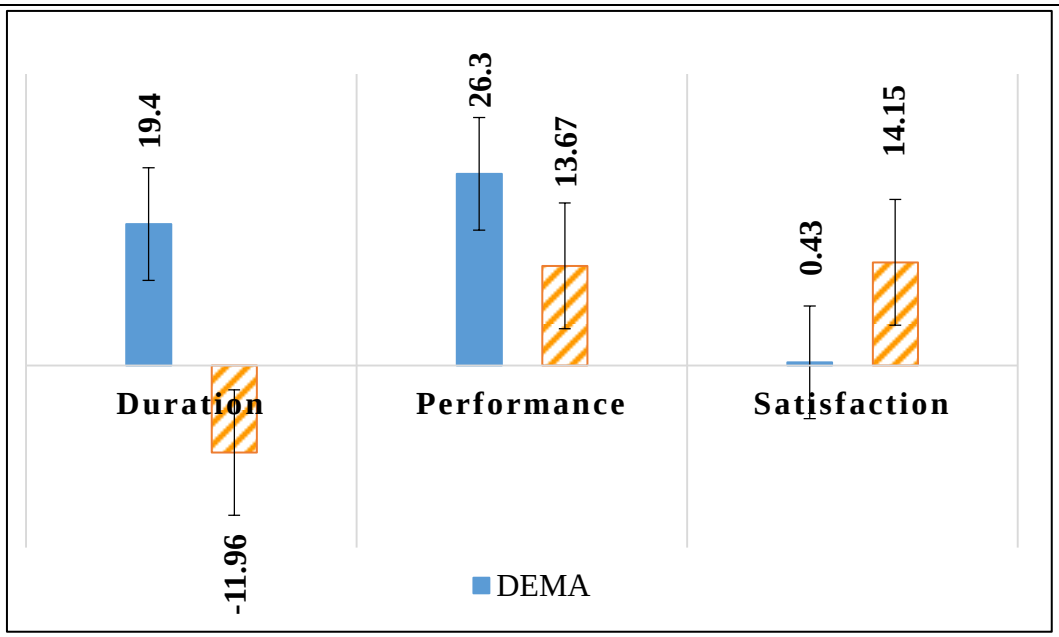
| ICF Level | N | Mean (SD) | Std Err | DF | t value | p value |
|---|---|---|---|---|---|---|
| Activity Level | 7 | 844.3 (564.6) | 213.4 | 13 | -0.31 | 0.7602 |
| Participation Level | 8 | 930.0 (501.0) | 177.1 | 12.166 | -0.31 | 0.7625 |
| Diff (1-2) | | -85.7143 | 275.0 | | | |

Following examination of primary activity duration and frequency, analysis of tendencies then focused on gaining insight into target primary activity self-reported COPM performance and satisfaction in light of duration.

Primary Activity, Self-Rated Performance ⎪ Satisfaction

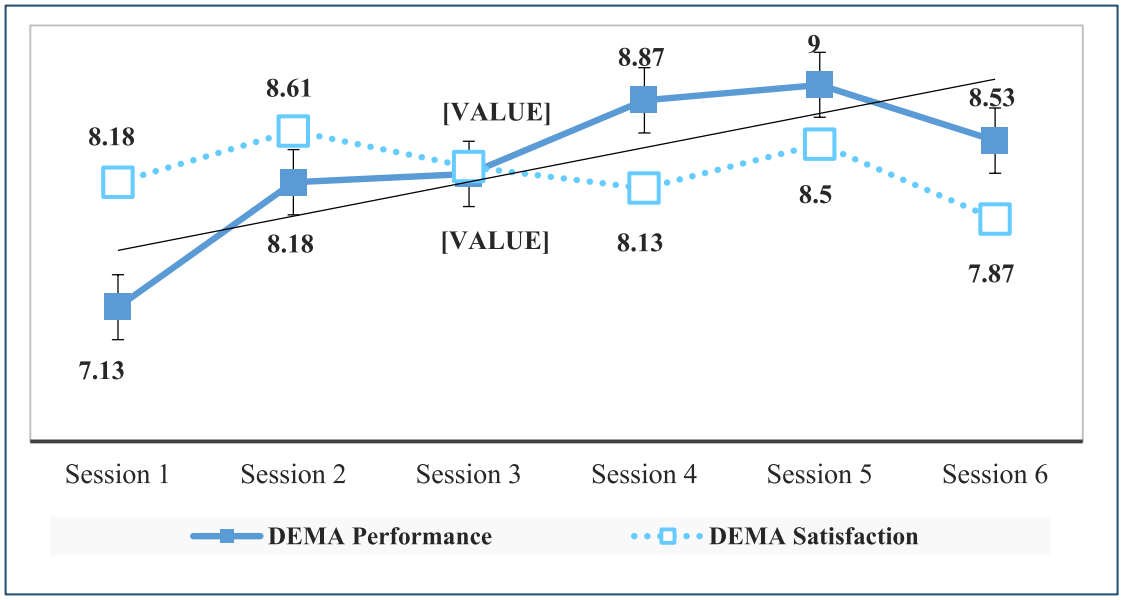
DEMA and IS group duration, performance and satisfaction mean percent change from session one to six is illustrated in Figure 16. Mean percent change was computed by calculating the difference between the two means being compared, then dividing the increase by the original number, which was then converted to a percentage. Previous observations revealed (refer to Table 27) DEMA group mean primary activity duration increase (19.4%) versus IS group decrease (-4.8%) session one versus six. The DEMA group demonstrated a 26.3% mean increase in self-rated activity performance, nearly twice that of the IS group. Meanwhile, the IS group demonstrated a mean increase in self-rated activity satisfaction of 14.15% compared to a 0.43% DEMA group increase. Data tendencies demonstrated a notable difference between primary target activity duration, as well as ratings of performance and satisfaction.

**Figure 16.** Mean % change: DEMA vs. IS compared difference session 6 vs. 1 for target primary activity duration, COPM ratings of performance and satisfaction.




In light of the apparent incongruence, additional care was taken to better visualize DEMA group mean self-rated performance and satisfaction across sessions (Figure 17). Examination of mean ratings across sessions one through six revealed a steady increase in self-rated performance, while a downward tendency was noted for self-rated satisfaction. An intersection of the two ratings occurred at session three. Mean self-rated performance increased by 19.63% while self-rated satisfaction decreased by 3.79%.

**Figure 17.** Mean DEMA COPM ratings of performance and satisfaction calculated from Likert scale ratings of 0 to 10.




The tendencies noted for DEMA versus IS target primary activity performance and satisfaction prompted inquiry into extent of participant engagement in secondary activities by each group.

Secondary Activity Engagement

In addition to the self-selected target primary activity, participants in both groups were asked to report the number of secondary activities in which they engaged during the weeks between sessions two through six. Qualitative themes indicated that DEMA participants expanded to secondary activities and experienced increased confidence to navigate challenges while optimizing degrees of being able. Closer examination of quantitative data specific to DEMA group secondary activity engagement clearly mirrored qualitative themes. The DEMA group self-reported an overall mean of 54.4 (4.56) self-selected secondary activities compared to the IS group mean of 32.8 (3.90),

indicating 65.86% greater secondary activity engagement by the DEMA group when comparing reports at session two versus session six (Table 30).

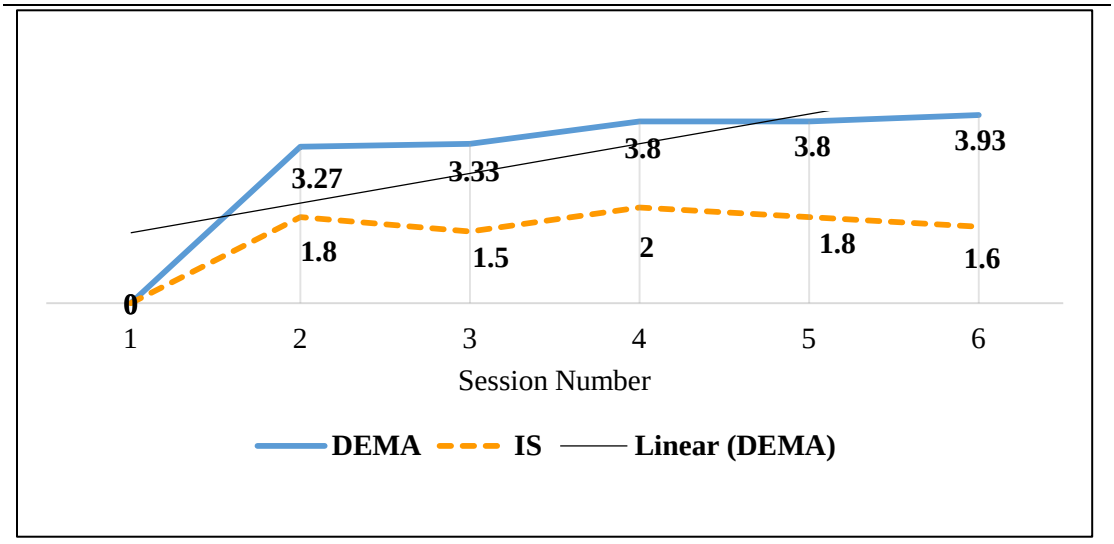
**Table 30.** DEMA vs. IS mean secondary activity frequency as reported each session.

| Session # | DEMA (n=17) Mean (SD) | IS (n=19) Mean (SD) |
|---|---|---|
| 1 | NA* | NA* |
| 2 | 3.27 (1.44) | 1.79 (1.23) |
| 3 | 3.33 (1.35) | 1.47 (1.72) |
| 4 | 3.80 (1.52) | 2.00 (1.25) |
| 5 | 3.79 (2.04) | 1.79 (0.79) |
| 6 | 3.93 (1.22) | 1.58 (1.26) |

*Secondary activities reported starting session two.

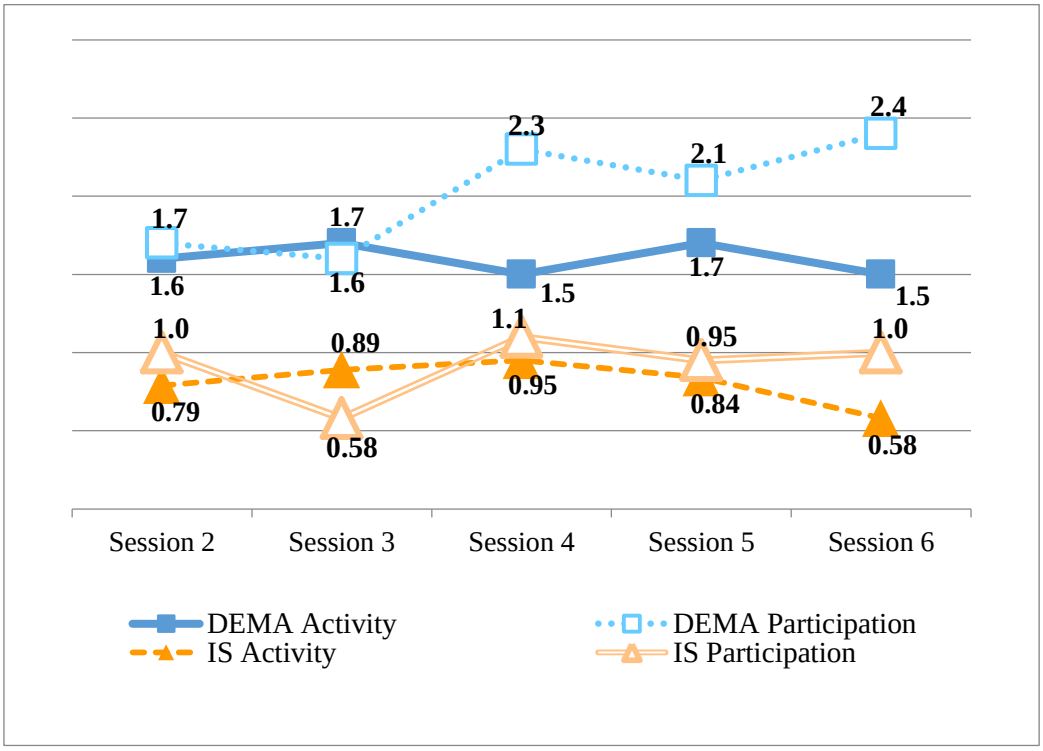
Examination of DEMA versus IS group mean number of secondary activities by session (Figure 18) demonstrated notably more secondary activity engagement by DEMA versus IS. Self-reported secondary activities in the DEMA group increased from 3.27 at session two to 3.93 at session six, yielding a 20.18% increase. Conversely, the IS group declined from a mean of 1.8 at session one to 1.6 at session six, demonstrating a 12.5% decrease.

**Figure 18.** Mean number secondary activities each session: DEMA vs. IS.



DEMA versus IS group self-reported secondary activities were then categorized and assigned to the ICF activity or participation level (Figure 19). Visual trending of secondary activities at ICF activity and participation levels for both groups illustrated a substantial divergence in overall secondary activity selection, particularly at the ICF participation level. DEMA secondary activities revealed a shift toward activity at the participation level as the intervention sessions progressed. Conversely, IS data tendencies showed marginal change in selection at the participation level when comparing session two to six. Calculation of percent change from session two to six demonstrated a 26.6% decrease in IS secondary activities at the ICF activity level. However, DEMA showed a 41.2% increase in secondary activity selection at the ICF participation level.

**Figure 19.** DEMA & IS mean secondary activity ICF activity vs. participation.



Qualitative themes indicated that moving from isolation to interconnectedness was multi-faceted and optimizing degrees of being able was a continuous process. Moreover, data tendencies indicated that DEMA participants tended to shift toward higher secondary activity frequency at the ICF participation level. To better objectify this shift, DEMA and IS group secondary activities were further sub-grouped by ICF level and an independent sample t-test was conducted to compare the number of secondary activity selections at the ICF level of activity versus participation in both the DEMA and IS group. In the DEMA group, there was a statistically significant difference in the number of secondary activities selected at the ICF participation versus activity level ($p = .0296$. In contrast, IS group secondary activity selections at the ICF participation level were not statistically significant (Table 31).

**Table 31.** Secondary activities sorted by ICF level within DEMA and IS group.

| Group | N | ICF Activity Mean (SD) | ICF Participation Mean (SD) | DF | t-value | p value |
|---|---|---|---|---|---|---|
| DEMA | 15 | 7.86 (3.71) | 10.21 (4.15) | 28 | 2.3017 | 0.0296* |
| IS | 19 | 3.68 (5.89) | 4.89 (3.77) | 36 | 1.6976 | 0.0982 |

*Note*. *= $p \leq .05$

Comparison of secondary activity at the ICF level of participation between the two groups (Table 32) did not demonstrate a significant difference.

**Table 32.** DEMA** vs. IS** secondary activities ICF participation. Difference between groups.

| DEMA Participation Mean (SD) | IS Participation Mean (SD | t value | p value |
|---|---|---|---|
| 10.21 (4.15) | 4.89 (3.77) | -1.876 | 0.0542 |

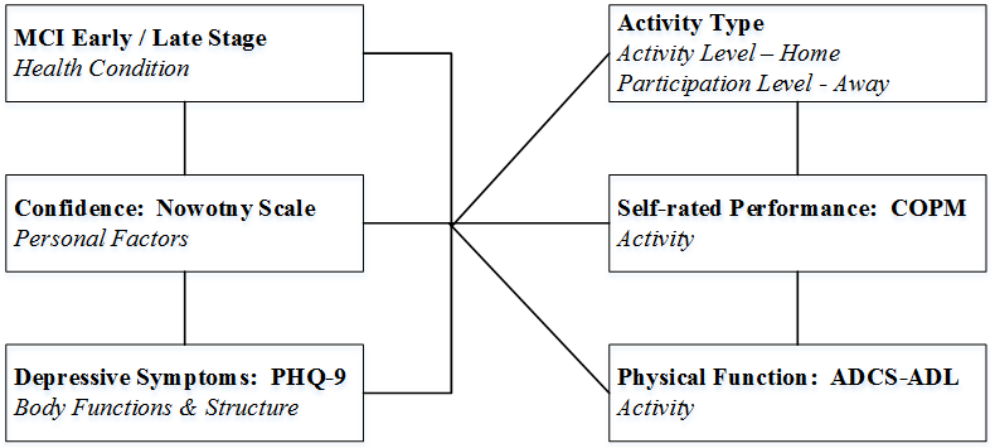
**(DEMA, n=15; IS, n=19)

Summary of Quantitative Findings

Findings are summarized in accordance with elements of the hypothesized model, beginning with data characteristics then proceeding through MCI stage, confidence,

depressive symptoms, activity type, frequency and duration. Finally, self-rated performance and physical function are summarized (Figure 5).

**Figure 5.** Hypothesized structural model of inter-related factors.




Summary of Findings – Data Characteristics

No significant difference was detected between groups, except that PwMCI in DEMA were statistically significantly younger than those in IS attention control (age = 71.23 for DEMA, age = 76.47 for IS attention control, p = .022). Baseline combined data indicated no significant difference in outcome measures at the start of the study.

Summary of Findings - MCI Stage

Baseline findings specific to MCI stage indicated that IS group PwMCI in late stage demonstrated negative correlation with depressive symptoms, and ADCS-ADL, indicating that IS PwMCI in late stage were more likely to present with fewer depressive symptoms and lower physical function than those in early stage. In the DEMA group, MCI late stage demonstrated a negative correlation with depressive symptoms, indicating that DEMA PwMCI in late stage were more likely to present with fewer depressive symptoms than those in MCI early stage.

At posttest, DEMA data demonstrated a negative correlation between MCI late stage and ADCS-ADL, indicating that PwMCI in late stage presented with lower physical function.

Summary of Findings - Confidence

Analysis of baseline relationships in the combined group demonstrated a negative correlation between confidence and self-reported depressive symptoms. The IS group demonstrated a negative association, which was not statistically significant (Aim 2).

At posttest, no significant associations were discovered among Nowotny Confidence, PHQ-9, COPM, and ADCS-ADL (Aim 3). In the DEMA group at posttest and follow-up, change in confidence did not significantly predict change in self-rated occupational performance (COPM) or physical function (ADCS-ADL (Aim 5). However, DEMA participants at posttest who were allocated to the ICF participation subgrouping demonstrated a statistically significant increase in confidence (Hypothesis 6.2). This posttest finding did not carry through to follow-up. Although not significant, the IS group demonstrated a mean decrease in confidence posttest from baseline. After subdivision by ICF level, potential difference in confidence between DEMA and IS could not be analyzed secondary to the limited number of subjects.

Summary of Findings - Self-Reported Depressive Symptoms

In the combined group at baseline, depressive symptoms were negatively correlated with confidence, indicating that PwMCI who reported higher confidence were less depressed. At baseline in both IS and DEMA, depressive symptoms (PHQ-9) were negatively correlated with MCI late stage, indicating that PwMCI in late stage were less likely to present with more depressive symptoms (higher PHQ-9 scores). In the DEMA group at baseline, depressive symptoms (PHQ-9) were negatively associated with

primary target activity type at the ICF activity level, indicating that those who reported fewer depressive symptoms were more likely to select the initial primary target activity at the ICF activity level.

From baseline to posttest, DEMA change in self-rated occupational performance (COPM) significantly predicted change in depressive symptoms (PHQ-9), indicating that as self-rated occupational performance improved depressive symptoms decreased (Hypothesis 4.1). Follow-up results, however, were not statistically significant (Hypothesis 4.2). Results for change in depressive symptoms (Hypothesis 6.2) indicated that DEMA participants allocated to the ICF participation subgrouping demonstrated a PHQ-9 mean score decrease by 1.86 points while the IS mean score increased by 0.26. Although neither change was statistically significant, the DEMA group mean posttest score demonstrated a categorical shift ($\geq 5$ = mildly depressed). Of those successfully contacted at follow-up, the DEMA group PHQ-9 mean score decreased to 1.77, demonstrating a 4.31 mean score change from baseline. However, the finding was not statistically significant.

Summary of Findings - Primary Activity Type

In the DEMA group at baseline, primary target activity at the ICF activity level demonstrated a negative correlation to depressive symptoms and a positive correlation with self-rated occupational performance (Aim 2). Such findings indicated that those who reported being less depressed were more likely to select the primary target activity at the ICF activity level. Additionally, those who rated higher occupational performance were more likely to select the primary target activity at the ICF activity level. At posttest,

no significant associations were noted between activity type and confidence, depressive symptoms, self-rated occupational performance or physical function.

Significant DEMA baseline difference was found by sub-grouped ICF level for the COPM and PHQ-9. PwMCI who scored higher on the COPM were more likely to initially select a primary activity at the ICF activity versus participation level ($p = 0.002$). Additionally, PwMCI who self-reported more depressive symptoms on the PHQ-9 were more likely to initially select a primary activity at the ICF participation level ($p = 0.008$). At posttest, those who were allocated to the ICF participation sub-group demonstrated a statistically significant increase in confidence. Those who initially engaged at the at the ICF activity level did not demonstrate a significant change in confidence.

When examining data tendencies, DEMA group primary activity mean duration increased session one to three and one to six, yielding a 19.4% mean duration increase. The IS group demonstrated an overall decrease in activity from session one to three and one to six. Neither DEMA nor IS demonstrated a significant difference in primary target activity cumulative duration when sub-grouped by ICF activity versus participation level.

Specific to mean primary activity frequency from session one to six, the DEMA group demonstrated a steady increase from 3.42 to 5.13 primary activity frequency per week, indicating a 50% mean overall increase in activity frequency compared to an overall decrease in activity frequency of the IS group (-38.25%).

Summary of Findings - Secondary Activity Type

Self-reported secondary activities in the DEMA group increased from a mean of 3.27 at session two to 3.93 at session six, yielding a 20.18% increase. Conversely, the IS group declined from a mean of 1.8 at session one to 1.6 at session six, demonstrating a

12.5% decrease. Moreover, DEMA secondary activities revealed a shift toward activity at the participation level as the intervention sessions progressed. Conversely, IS data tendencies showed no change in selection at the participation level when comparing session two to six.

Summary of Findings Related to Secondary Activity Type by ICF Level

Examination of DEMA and IS secondary activity by ICF level revealed a tendency toward the participation level in the DEMA group as sessions progressed. Additionally, the data showed a 41.2% DEMA group increase in secondary activity selection at the participation level of the ICF when comparing session two to six. Visual trending of secondary activities at ICF activity and participation levels for both groups illustrated a substantial difference in overall secondary activity selection, particularly at the ICF participation level. IS data trending showed virtually no change in selection at the participation level when comparing session two to six. Additionally, a 26.6% decrease in secondary activities was noted at the ICF activity level.

In the DEMA group, there was a statistically significant difference in number of secondary activity selections at the ICF participation versus activity level. In contrast, IS group secondary activity selections at the ICF participation level were not statistically significant. Comparison of secondary activity at the ICF level of participation between the two groups did not demonstrate a significant difference, likely due to a limited number of subjects.

Summary of Findings - COPM Self-Rated Performance

In the DEMA group at posttest, change in self-reported occupational performance (COPM) predicted change in depressive symptoms. In the DEMA group at posttest, the

DEMA group demonstrated a 26.3% mean increase in self-rated activity performance, nearly twice that of the IS group. Examination of DEMA group mean ratings across sessions one through six revealed a steady increase in self-rated performance while a downward tendency was noted for self-rated satisfaction. Comparison of session six to one demonstrated an IS group mean increase in self-rated activity satisfaction of 14.15%. Comparatively, the DEMA group demonstrated a modest 0.43% increase. An intersection of performance versus satisfaction ratings occurred at session three. DEMA mean self-rated performance increased by 19.63% while self-rated satisfaction decreased by 3.79%.

Summary of Findings - Physical Function

Baseline IS data indicated a negative correlation between physical function (ADCS-ADL) and MCI late stage, indicating that those in late stage MCI presented with lower physical function. Baseline DEMA data demonstrated a negative correlation that fell just short of statistical significance ($p = 0.0588$).

Posttest from baseline difference in DEMA physical function (ADCS-ADL) participation level sub-score demonstrated a statistically significant sub-score improvement, while the IS group demonstrated a sub-score decrease. Additionally, the data demonstrated a significant difference in sub-score change between the DEMA and IS groups. The data did not demonstrate continuance of significant difference through follow-up.

Summary of Aims

Posttest and follow-up findings indicated significant associations among select outcome measures while follow-up findings indicated that change in self-rated

occupational performance (COPM) predicted change in depressive symptoms. Additionally, the DEMA group demonstrated a statistically greater number of secondary activity selections at the ICF participation level. Moreover, examination of posttest physical function (ADCS-ADL) sub-score change at the ICF participation level demonstrated statistically significant change in the DEMA group as well as a significant difference between DEMA and IS. Findings specific to null hypotheses are summarized in Table 33.

**Table 33**. Summary of Aim Null Hypotheses.

| Aim | Null Hypothesis | Accept | Reject | Finding |
|---|---|---|---|---|
| 2 | At baseline, no statistically significant relationships exist among MCI stage, confidence, self-reported depressive symptoms, activity type, self-rated activity performance and physical function. | | X | ▪ Baseline combined demonstrated negative association between confidence and depressive symptoms.<br>▪ Baseline IS group PwMCI in late stage demonstrated negative correlation with depressive symptoms<br>▪ Baseline IS group PwMCI in late stage demonstrated negative correlation with physical function.<br>▪ Baseline DEMA MCI late stage demonstrated a negative correlation with depressive symptoms<br>▪ Baseline DEMA activity type at ICF activity level demonstrated a negative correlation to depressive symptoms<br>▪ Baseline DEMA activity type at ICF activity level demonstrated a positive correlation with self-rated occupational performance |
| 3 | In DEMA group at posttest, no statistically significant relationships exist among MCI stage, confidence, self-reported depressive symptoms, activity type, self-rated activity performance and physical function. | | X | ▪ Posttest DEMA MCI late stage demonstrated negative correlation with physical function<br>▪ Analysis by ICF level indicated statistically significantly lower depressive symptoms at activity versus participation level. |
| 4 | In DEMA group at posttest and follow-up, change in confidence, activity self-rated performance, and physical function does not predict change of depressive symptoms. | | X | ▪ Posttest DEMA change in self-reported occupational performance (COPM) predicted change in depressive symptoms |
| 5 | In DEMA group at posttest and follow-up, change in confidence does not significantly predict change of self-rated performance or physical function. | X | | ▪ Change in confidence did not statistically significantly predict change of self-rated performance or physical function. |
| 6 | In DEMA at posttest and follow-up when sub-grouped by ICF level, no statistically significant difference exist in change of confidence or depressive symptoms. | | X | ▪ Posttest DEMA at ICF participation level demonstrated significant increase in confidence. |

# Chapter V

## Discussion

The prevalence of mild cognitive impairment (MCI) is nearly four-times greater than dementia[7,8] and as many as 48% of persons with MCI (PwMCI) transition to a form of dementia in fewer than 60 months.[3,11-13] Currently, there is no known cure, no verified strategy to stop or reverse MCI.[72] PwMCI experience disengagement from personally meaningful activities and diminished participation that impacts both PwMCI and their caregivers.[19,39,40] Studies indicate that cognitive changes and self-care confidence adversely impact self-care behaviors,[41] while depressive symptoms play a predictive role in independent activities of daily living (IADL) such as ability to shop, handle finances and independently use transportation.[42,43] Notably, persons with cognitive impairment report more than three times as many hospital stays as those who are hospitalized for some other condition.[46] MCI cascade effects of functional decline and increased dependency frequently necessitate premature admission to alternative living settings or skilled care.[11,15] Absence of a known cure for MCI further escalates the urgency that accompanies daunting challenges to implement innovative, multi-faceted interventions that are reproducible and scalable.

Current U.S. public health policies and plans[89,90,172] advocate for innovative dementia-capable efforts across the preventive spectrum. The Daily Engagement of Meaningful Activity (DEMA) study was a well-designed, NIH-funded two-group randomized trial intended to ascertain feasibility, effect size, acceptability and usefulness of a multicomponent intervention program for PwMCI. Parent study findings demonstrate promising results[47,49,65] that indicate potential for program refinement and

expansion. Studies that directly address multicomponent interventions for PwMCI are rare,[47,136,173] making the opportunity to conduct a secondary analysis and capture insight to both outcome and process data not only prudent, but imperative.[174] Secondary data analysis affords opportunity to explore high-impact considerations, such as how PwMCI respond to the DEMA intervention, as well as the delicate balance between participant outcomes and perceived program value. Moreover, information gleaned from this secondary analysis will support ongoing efforts toward future studies, as well as reproduction and scalability of the DEMA intervention. Mechanisms by which cognitive impairment affects function, level of activity engagement and self-perceived performance are not currently well-defined. Less understood are common themes that influence PwMCIs' likelihood of response to intervention. The model proposed for this secondary analysis took fundamental, initial steps to examine potential baseline, posttest and follow-up relationships among confidence, self-reported depressive symptoms, activity type, self-rated performance and physical function.

Participant Characteristics

Similar to other activity-focused and behavioral intervention studies for persons with dementia (PwD) and PwMCI, this study sample was comprised of adults over 60 years who presented with a confirmed diagnosis and benefited from assistance of a vested, informal caregiver.[48,49,175,176] Data characteristics demonstrated a significant difference in age between DEMA and IS. However, both IS and DEMA means were positioned in the 70-79 cohort parameters that are commonly employed by the WHO, U.S. Department of Health and Human Services National Center for Health Statistics, National Institute on Aging and National Institutes of Health.[177-180]

MCI Stage

Because the feasibility study sample was further sub-grouped by intervention and control, intermittent challenges to statistical power were not surprising. Baseline findings of higher levels of depressive symptoms for combined and Information Support (IS) group in early stage MCI remain consistent with earlier studies.[111,117,181,182] Although not statistically significant, baseline DEMA MCI early stage mean depressive symptoms (PHQ-9) were in the "mild depression" category (≥ 5) and nearly twice that of late stage. Baseline and posttest physical function was negatively associated with MCI late stage, implying lower physical function at late stage. Other studies note that PwMCI, when compared to healthy controls and PwD, display detectable deficits in instrumental activities of daily living (IADL), demonstrating intermediate scores compared to controls and persons with Alzheimer's Disease (AD).[96,101,182,183] Additionally, PwMCI demonstrate slower speed of task performance[100] and individuals with multiple domain MCI demonstrate more impaired IADL than those with single domain.[184] While studies were located that address functional changes associated with amnestic-MCI (a-MCI) versus non-amnestic-MCI (na-MCI),[6,185] this author was unable to locate additional study findings that specifically distinguish significant Alzheimer-s Disease Cooperative Study-Activities of Daily Living (ADCS-ADL), or other activities of daily living assessment score associations with MCI early versus late stage, indicating a novel finding.

Depressive Symptoms │ Confidence

Analysis of baseline relationships in the combined group demonstrated a negative association of confidence with self-reported depressive symptoms. O'Shea and colleagues propose that self-efficacy (confidence) moderates the relationship between

self-rated memory function and depressive symptoms.[186] Studies designed to address chronic health conditions with co-morbid depression and/or cognitive impairment[41,187-189] indicate that self-efficacy, or task specific confidence, plays a significant role in behaviors such as self-care and on-going self-management. Quantitative analysis of this small sample did not demonstrate statistically significant findings specific to change in confidence as a predictor of change in depressive symptoms ($p = 0.0579$) or other select outcome variables (Table 14). However, qualitative themes supported the proposition that awareness and change in confidence appreciably interacts with and serves as antecedents to changes in emotional affect, self-perceived occupational performance and physical function. For example, participants voiced improved awareness of limitations paralleled by readiness to ask for help. As one participant stated: "… as opposed as trying to go and do something and saying there's no help, just go ahead and get help period and be open to somebody helping me with the difficulty" [56.13-14]. When asked about benefits of the program, one participant stated "…opening up and feeling more confident and stronger… I tend to take more charge of the situation or an intervention than I did before" [56.16-17]. Another participant discussed their awareness of the need for focused effort and that making time to ensure practice of valuable activities made a positive difference in one's outlook: "as far as my exercise there's times in the morning I don't really want to do that but I say 'I've got to do that', and when I do that then I feel better [01.34]. DEMA participants voiced a sense of mastery whereby they perceived improved problem-solving benefiting functional performance: "…when I go in a store now I kind of line myself up with a sign or something on the building, then I try to remember that when I come out, and that helps quite a bit as far as finding my car"

[24.18]. Moreover, participants were able to articulate objective improvements specific to required daily functions: "…my work activities, learning to break them down into smaller parts, and making lists, that has really helped me" [07.17]. The interface of the aforementioned qualitative themes reveal two core keys of engagement: awareness and confidence. The DEMA intervention process supported increased awareness of limitations and fostered confidence.

Activity Selection

Activity was examined in two ways. Primary activity and secondary activities were both examined by International Classification of Functioning and Disability (ICF) level and duration. DEMA participants who self-reported more depressive symptoms were more likely to initially engage at the participation level. Research shows that recent health events such as a diagnosis of MCI can elevate perceived life adversity and elevate prevalence of depression.[190] Studies indicate that social support and being embedded in a supportive network may reduce the risk for depression in older adults.[191] Factors of social relations significantly associated with depression include extent of social support, quality of relations and presence of confidants.[191] DEMA qualitative themes and participant comments offer contextual insight into the value of partnership and shared interest: "I seek people who share the same interests and also share interests in the same activities…It's just that maybe there is a feeling of camaraderie" [40.49-50]. Another PwMCI shared, "I think everybody that (spouse) and I associate with have a part. …It takes a lot of people to help you…we do things together…they're just great people" [12.17, 44]. Such statements reflect the perceived value of DEMA involving a trusted confidant, such as a spouse or close relative, into the goal-setting and problem-solving

discussions. Moreover, PwMCI statements reflect a sense of belonging associated with interactions that extend beyond the immediate caregiver.

Conversely, DEMA participants who scored higher on the Canadian Occupational Performance Measure (COPM) at baseline were more likely to initially engage at the ICF activity level. While the parent study did not incorporate in-depth assessment of pre-morbid functioning or personality profiling, historical life habits and personality traits may have shaped participant selection of quiet recreation such as gardening, playing the piano or painting. Moreover, environmental factors such as temporary caregiving duties by the PwMCI for a loved one, may have influenced ratings of activity importance. For example, one DEMA PwMCI was faced with temporarily caring for his spouse who had recently undergone surgery, thereby impacting primary activity selection:

> "…the laundry… I would go down in the basement and she would sort the clothes up there… and then I would go down and throw them in the washer. … then I would call her …and she would tell me how much detergent… bleach … fabric softener to put in, … and then what cycles to cycle the washer on" [24.20].

Quality of life and disability literature, along with aging studies, affirm that participation is a primary goal for persons with disability and an important health outcome across the prevention spectrum.[20,192-195] Additionally, researchers posit that participation embraces the multifariousness of human functioning by surpassing, yet is not fully explained by, activity level.[24,195-198] At posttest, DEMA participants allocated to the ICF participation subgrouping demonstrated a statistically significant increase in confidence. Meanwhile, although not statistically significant, DEMA ICF participation level subgroup posttest and follow-up depressive symptoms appreciably shifted from the "mildly depressed" category to "not depressed". Such a categorical shift in depressive

symptoms (PHQ-9) is considered clinically relevant and meaningful.[63,169] This interesting parallel signifies interactions among adaptation, coping mechanisms and skill-building via the DEMA program's emphasis on applied problem-solving and sufficient engagement frequency.[183,195,199] As sessions progressed, DEMA group primary and secondary activity mean durations increased while the IS group demonstrated an overall decrease. Studies show that depression is associated with lower participation frequency, and that when activity level is more limited participation is further restricted.[195,200-202] Conversely, evidence attests to physical, functional and cognitive benefits of sufficient frequency of engagement.[200,203-206]

Both qualitative and quantitative findings indicate the added-value of a strengths-based approach whereby PwMCI self-identify activities and related goals. Although influenced by body structures and function, personal and contextual factors, the DEMA intervention supported prioritization and goal-setting for activities identified as most challenging by the PwMCI-caregiver dyad. The process of problem-solving supported activity self-management and dosing, increasing the PwMCI's ownership and autonomy.

Performance | Satisfaction

DEMA participants reported higher self-rated activity performance than IS, while the IS group reported higher activity satisfaction (Figure 16).[65] This paralleled qualitative findings, possibly indicating PwMCIs' realization of personal potential to attempt more. As experiences of engagement progressed, self-perceived performance and sense of mastery particular to the primary activity increased, yielding a relatively lesser degree of satisfaction with activities of engagement that were initially more satisfying. This counter-intuitive finding may be in part explained by the dual process

model of coping and response shift theory.[207-209] Response shift phenomena refers to a change in internal standards, values or conceptualization of quality of life (QOL) in light of health changes.[195,208] Response shift implies an adjustment in the meaning of one's self-assessment of satisfaction that is commonly linked to three posited changes:[209] (a) recalibration, (b) reprioritization and (c) reconceptualization. Recalibration involves a change in internal standards of measurement while reprioritization involves change in values. Reconceptualization entails redefinition of the construct.[208,209] DEMA participants engaged more extensively in both primary and secondary activities. Data tendencies demonstrated crossover that occurred at session three (Figures 15, 17) for both frequency and self-rated primary activity performance. As frequency of DEMA activity and performance increased, satisfaction appeared to vacillate. In accordance with response shift theory,[208] DEMA participants who steadily increased engagement frequency experienced a change whereby improved performance and increasing sense of mastery prompted internal adjustments in measurement standards and reconceptualization of self-rated activity satisfaction. A similar phenomenon applies to IS group participants. IS primary and secondary activity frequencies were appreciably less than that of DEMA, while primary self-rated satisfaction appeared more robust (Figure 17). As frequency of IS activity decreased, satisfaction continued to rise. IS participants who steadily decreased engagement frequency may have experienced a change in internal measurement standards – an artificial "lowering of the bar", so to speak – and thereby re-conceptualized self-rated activity satisfaction. Interestingly, studies indicate that persons well-adapted to their disability may be similarly satisfied with their participation level, even if it is restricted.[198] Another consideration related to difference between DEMA and

IS satisfaction is the instrumentation that was utilized. The COPM is based on the definition of occupational performance, where occupation is the interface between the person and the environment.[27] While COPM ratings of activity importance, performance and satisfaction are sensitive to change in occupational performance over time, the instrument is not designed to assess response shift. Use of a generic quality of life measure such as the Quality of Life Index[210] may have enhanced insight into response shift and perception of satisfaction across life domains.[211] QOL may be understood as the sum of cognitive and emotional responses that one experiences associated with personal achievements in context of culture and values, accounting for personal goals, expectations, standards and concerns.[212-216] Although not assessed as an outcome of the parent study, DEMA qualitative findings indicate participant shift in perceived life quality. "…just the process of going through daily activities, weekly activities, trying to be positive…knowing that it is going to help us have a better life" [03.52]. Additionally, qualitative themes indicate as sense of fulfillment and accomplishment, akin to satisfaction.

> "When you build something complicated and you stand back and look at it and think that you did a good job…there's probably nobody else in my neighborhood that could do them… I still think I do a good job on them… there's satisfaction and completion" [09.35-36].

When comparing the DEMA to the IS group, DEMA participants engaged in over twice as many secondary activities and nearly twice as many of those secondary activity selections were at the ICF participation level (Figures 18, 19). Realizing that the DEMA program was intended to improve engagement in meaningful activities, it is encouraging but not surprising that the intervention group engaged in more secondary activities than the control group. Even more encouraging about the DEMA group is the significant

difference in number of secondary activity selections at the ICF participation level. Although not statistically significant, the IS group also selected more secondary activities at the ICF participation level. Recall that lower participation frequency has been shown to be associated with depressive symptoms.[200]

Both qualitative and quantitative findings reveal key ingredients of self-perceived change and response shift. PwMCI in the DEMA group voiced self-perceived, positive change in primary activity performance. Qualitative findings indicate that expressions of satisfaction more globally implicated quality of life. Comparatively, less robust ratings of satisfaction implicated a particular activity whilst shaped by reconceptualization of perceptions and recalibration of expectations.

Physical Function

Posttest from baseline physical function (ADCS-ADL) participation sub-score (keeping appointments, get around outside home, go shopping at a store) improvement was statistically significant for DEMA. Additionally, a significant difference was noted between the DEMA versus IS group. Research confirms increased difficulty for PwMCI with instrumental activities of daily living (IADL) at the participation level. Activities that involve 'high cognitive demand' such as shopping, are strongly associated with MCI;[97] further emphasizing both functional and clinical significance of the participation sub-score findings. Regardless of whether initial target primary activity engagement was selected at the ICF activity or participation level, DEMA group PwMCI demonstrated a statistically significant improvement in the physical function (ADCS-ADL) participation level sub-score. However, this should be viewed in context of the understanding that data

tendencies demonstrated a higher number of DEMA secondary activity selections at the ICF participation level (Figure 19).

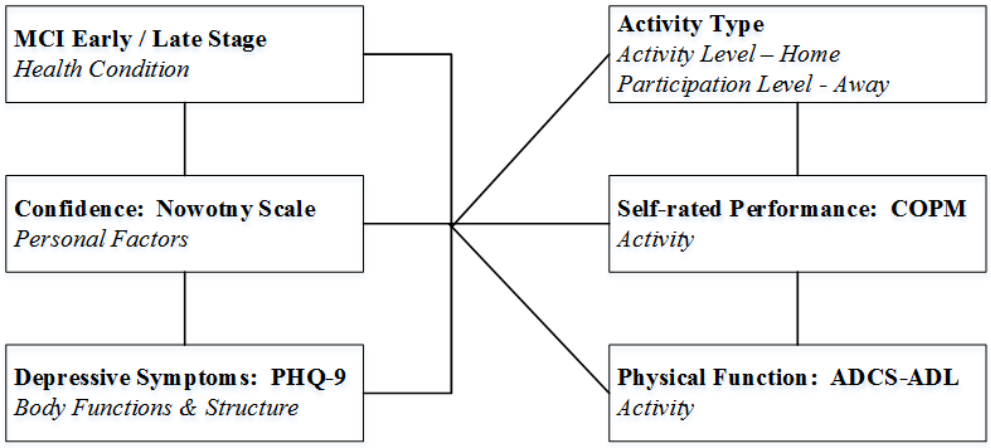
Significant improvements in participation level physical function offer rays of hope for PwMCI and echo qualitative theme categories: II) Engagement entails making adjustments while optimizing degrees of being able; IV) Working through and around by re-framing and re-investing. DEMA participants note environmental factors, like caregiver assistance, as integral to successful participation: "…we will find a way to solve problems as they arise, and we have the ability to do that and we'll do it; we'll do what we need to do" [03.21]. Likewise, participants cite improved capacity to work from identified options and strengths: "I've learned some new tools on how to work around my memory problems…making lists and breaking down the activity into smaller, manageable pieces" [07.05]. Ultimately, participants refer to improved awareness and openness that foster confidence to seek and benefit from help: "…what to expect and what your family would start expecting, and that there is help out there and you can get some help to deal with it…" [81.07]. The DEMA program supports a progressive interplay among awareness, confidence, contextual and personal factors that facilitates PwMCI expansion of engagement, regardless of whether initial activity selection is at the ICF activity or participation level.

Model Considerations

While quantitative results specific to aims two through five were promising, they did not fully support the initially proposed model (Figure 5). Of the relationships in the DEMA data at baseline, only the negative correlation between MCI late stage and physical function continued through posttest. While change in self-rated activity

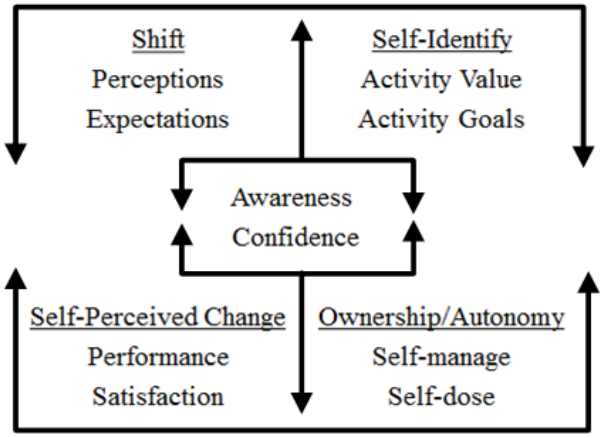
performance predicted change in depressive symptoms, change in confidence did not predict change of activity self-rated performance or change of physical function. Posttest DEMA demonstrated a statistically significant increase in confidence when primary activity was sub-grouped by ICF level. Yet, whether initial target primary activity engagement was selected at the ICF activity or participation level, the DEMA group demonstrated a statistically significant improvement in the physical function (ADCS-ADL) participation level sub-score. Understandably, the limited sample size may have precluded comprehensive model validation.

**Figure 5.** Hypothesized structural model of inter-related factors.




However, compelling qualitative themes and clinically meaningful change in depressive symptoms, paired with noticeably more activity engagement at the ICF participation level and significant change of the physical function (ADCS-ADL) participation sub-score prompted model modifications. The proposed PwMCI Engagement Model (Figure 20) evolved from a perpetual retroductive approach to the convergence of theoretical underpinnings, qualitative themes and quantitative findings.

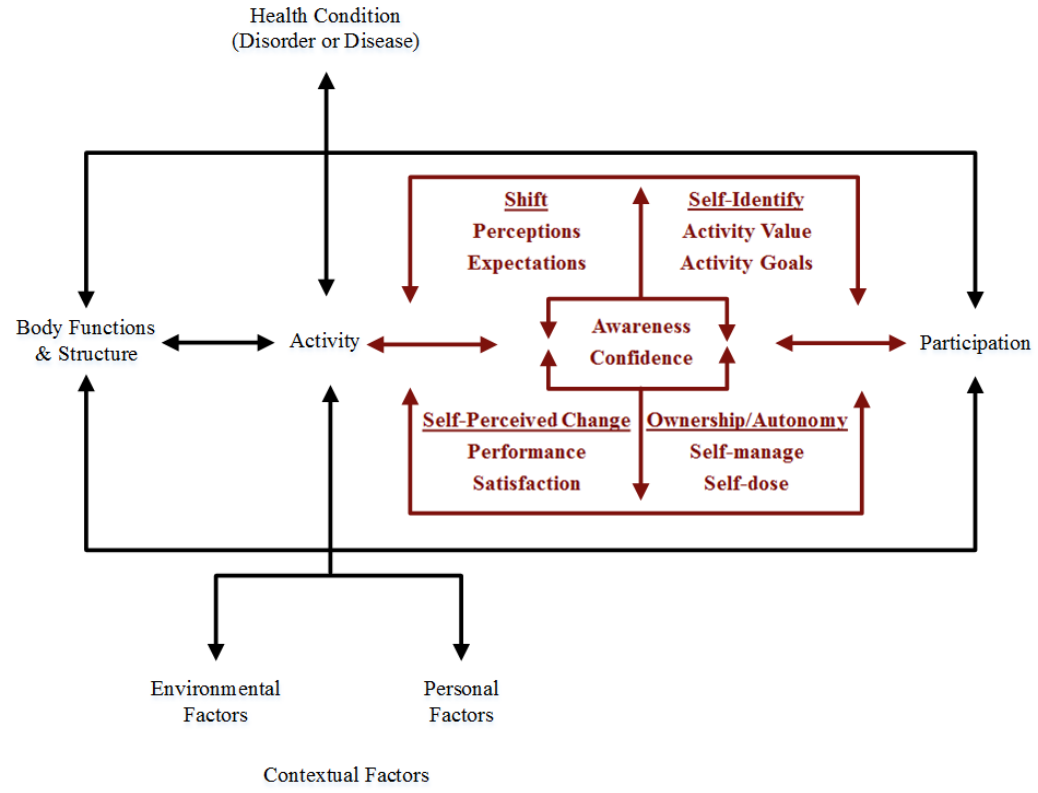
**Figure 20.** PwMCI engagement model.




At the model's core is PwMCIs' awareness and confidence. DEMA participants expressed increased awareness and enhanced confidence to employ problem-solving principles while asking for and benefiting from help. Surrounding the core are four interactive sections that illustrate essential ingredients of engagement. Through self-identified activities and personalized goal-setting, participants afforded themselves permission and power to focus engagement efforts on areas of greatest personal value. Progressive application of strength-based problem-solving techniques empowered participant ownership of activity self-management and self-dosing. Completion of activity logs along with bi-weekly discussions guided by the nurse intervener reinforced prioritization and activity engagement. Examples included, but were not limited, to improved activity planning, pacing and refinement of activity performance. Self-rated activity performance improved, likely associated with progressive increases in engagement frequency and duration. Satisfaction also improved, tempered by congruent shifts in DEMA participants' perception. Adjusted expectations (shifts) illuminated ever-increasing realization of capacity to expand primary and secondary activity engagement.

The PwMCI engagement model, when positioned within the ICF model (Figure 21), illustrates PwMCI expansion of activity engagement at both the activity and participation level. Expansion of engagement influences and is influenced by contextual factors. Environmental factors, such as caregiver teamwork, family and social support, facilitate PwMCIs' further expansion of activity engagement. Personal factors, such as lifestyles and habits, are adjusted as the process of perpetual engagement unfolds. The multifaceted intervention design of the DEMA program supports PwMCI expansion of engagement at both ICF activity and participation levels.

**Figure 21.** PwMCI engagement model interface with ICF.




Future Study Considerations

DEMA is an innovative program, intended to help chart a course for strength-based, multicomponent, biopsychosocial interventions. Opportunity exists to test and

further refine the proposed PwMCI engagement model in future DEMA studies. However, a common challenge to innovative efforts and model testing is paucity of available instrumentation capable of comprehensive capture of hypothesized outcomes at study outset. Beyond continuance of phenomenological methodology, updated instrumentation is now available for consideration. Future studies should incorporate sufficiently robust outcome assessment instrumentation to test the newly proposed model and better ascertain PwMCI response to intervention. The ADCS-ADL, although valuable for ascertaining basic and instrumental activities of daily living in persons with Alzheimer's Disease,[64,166,167] may not fully address the complex activities performed by community-dwelling PwMCI. It therefore may lack sensitivity to change across ICF levels of activity versus participation. The Alzheimer's Disease Cooperative Study-Activities of Daily Living Scale adapted for PwMCI (ADCS/MCI/ADL24)[217] is sensitive to detection of initial functional changes associated with early diagnosis of MCI. Such a tool could prove more sensitive to monitoring the evolution of functional changes in PwMCI, tracing patterns of change in both higher order functional abilities and basic ADL. Recent studies affirm potential added-value of the Advanced Activities of Daily Living Tool (a-ADL).[218] This instrument is designed as a semi-structured interview for both self and proxy-report, and demonstrates excellent reliability (test-retest, patient-proxy), face, content and construct validity.[199] It employs the terminology and scoring system of the ICF.[183] Item scores range from 0 (no problem) to 4 (total problem) based on the total number of a-ADL relevant for an individual, according to the manner in which they perform the activities and the underlying impairment. Additionally, the a-ADL references pre-morbid functioning of each participant, and thereby affords

computation of several disability indices, of which the global, cognitive and physical indices are already validated for use in an older adult population with cognitive changes. Lower indices scores are expressed as percentages with lower scores indicating more independence.[218] The instrument takes each participant as their own reference, which could limit comparison across subjects. This limitation is likely offset by the advantage of reference to pre-morbid functioning.[218]

While studies confirm the value of the Canadian Occupational Performance Measure's (COPM) capacity to objectify perceived activity importance, performance and satisfaction, the instrument's underlying design does not readily permit comparison across clients.[27,59,164,219] In contrast, the Assessment of Life Habits (Life-H)[220,221] considers participation in activities and roles, includes satisfaction with participation, permits comparison across clients, accounts for social participation, is valid for use with older adults with and without cognitive impairment and demonstrates sensitivity to change. This instrument was recently modified – Assessment of Life Habits, modified (Life-Hm) – to incorporate importance of activities and roles and validated for application with older adults.[222] Assuming the instrument is confirmed valid for persons with cognitive impairment, employment of the Life-Hm in future DEMA studies could potentially enhance insight into social participation and permit comparison across subjects.

Similar to previous challenges surrounding the measurement of balance confidence in older adults at fall risk,[223 224,225] there are unique challenges associated with measurement of activity confidence and self-efficacy in PwMCI. While the Nowotny Confidence Subscale is typically used to quantify self-reported confidence in one's own

ability, it was validated and commonly employed with the oncology population.[62,163] As such, opportunity exists to design and validate instrumentation aimed to better ascertain activity confidence and self-efficacy in PwMCI.

The parent study demonstrated promising findings specific to feasibility, acceptability, and usefulness.[47,65] Yet, it is hypothesized that the DEMA program impact could be further enhanced. Studies across various patient populations support the notion that spaced "reinforcement sessions" would further encourage maintaining performance of desired health behaviors[226,227] such as increased frequency and duration of engagement, and increased engagement at the ICF participation level.[228,229] Employment of longitudinal follow-up would further enhance insight into PwMCI experience, impact of potential change in MCI stage and challenges to perpetual engagement commonly associated with self-management of co-morbid conditions.[230,231]

Over the next two decades, nearly 3 million baby boomers, whose comfort level with technology is greater than previous generations,[232] will reach retirement age each year. As such, opportunity exists to explore intervention delivery using technological options such as skype and electronic activity monitoring. Additionally, there is opportunity to adapt intervention delivery for assisted living settings and through personnel such as occupational therapists, social workers, activity directors or even trained volunteers.

Finally, options for MCI interventions should be weighed in light of short-term and long-term implementation costs versus PwMCIs' and caregivers' benefit.[233] Economic estimates by researchers in the United Kingdom and U.S. indicate that improved diagnosis of dementia and MCI, combined with as little as a 1% per year

decline in prevalence of moderate to severe cognitive impairment, would yield a worthwhile decline in Gross Domestic percentage of expenses for long term care services.[172,233 234] Future DEMA studies should incorporate methods to ascertain parallel fiscal benefits of on-going activity engagement, such as reduced hospital admissions, falls and reductions in premature transitions to long-term skilled care.

Limitations

The parent study and this secondary analysis have several limitations. First, the subject sample was recruited from a singular university hospital. The sample was comprised of primarily Caucasian, English-speaking persons with a mean education exceeding 15 years, and the majority of participants for both groups were retired. As such, there was a lack of minority participants (African American, Hispanic American). Study eligibility required both PwMCI and caregivers to possess a working phone in the home or daily access to a telephone. Requirement of regular phone access, in light of mean education and the requirement to be English-speaking, could limit generalizability of the findings to more highly educated, English-speaking PwMCI who are chiefly Caucasian. Future research is recommended that includes more diverse PwMCI and informal caregivers. Second, although PwMCI often have sufficient cognitive abilities to communicate choices and preferences,[235] the qualitative data from PwMCI may be less robust due to possible MCI stage-related language declines such as ability changes in topic maintenance, word finding, and pragmatics of emotion and attitude expression. Future research may incorporate speech-language baseline assessment to objectify and account for possible changes in auditory comprehension and verbal expression.

# Chapter VI

## Conclusion

This secondary analysis investigated expected relationships among and potential effects of health condition (MCI stage), body functions and structure (self-reported depressive symptoms), and personal factors (confidence) on activity type, self-rated performance and physical function. Results clearly indicate the substantial and positive impact of the Daily Engagement of Meaningful Activities program (DEMA). Literature and practitioners alike confirm the urgent demand for impactful interventions that improve patient engagement whilst attenuating functional decline and premature changes in living setting.[22,23,91] While studies confirm that persons with MCI (PwMCI) benefit from exercise, cognitive intervention and the like[129,136-138], few studies have focused on equipping both the PwMCI and informal caregiver with self-directed, strength-based, problem solving strategies that are readily applicable to help them achieve improved engagement with added potential of preserving personal, family and societal roles.[47-49,173] Moreover, fewer still have addressed affordability and cost-containment options associated with a multicomponent program that involves both the PwMCI and informal caregiver.[236] Results of this secondary analysis contribute to the body of knowledge intended to illuminate practitioner insight to PwMCIs' interplay among confidence, self-perception of engagement, activity type, depressive symptoms, self-rated performance and physical function. Moreover, findings from process outcome emphasize the unique value of employing guided, strength-based problem-solving to foster activity and participation.

Future research should explore the extent to which DEMA impacts physical function as well as activity and participation in the home and community. First, a larger, randomized controlled longitudinal trial is necessary to further evaluate efficacy and impact of perpetual activity engagement. Second, future research should explore directly whether the DEMA intervention reduces participation restriction in PwMCI and leads to improved quality of life outcomes, including increased activity engagement in the home and community. Third, opportunity exists to enhance interdisciplinary collaboration with the express intent to catalyze replicability, scalability and multi-setting implementation of this powerful, multi-faceted intervention.

Appendix 1: Canadian Occupational Performance Measure (COPM)[27]

| **Step 1:**<br>**Identification of Occupational Performance Issues**<br>To identify occupational performance problems, ask client to identify daily activities which they want to do, need to do or are expected to do but can't do, don't do or aren't satisfied with how they do it. | **Step 2: Rating Importance**<br>Using scoring card provided, ask client to rate, on a scale of 1 to 10, the importance of each activity. |
|---|---|
| **Step 1A: Self-Care** | **Importance** |
| **Personal Care**<br>(e.g., dressing, bathing, feeding, hygiene) | |
| **Functional Mobility**<br>(e.g., transfers, indoor, outdoor) | |
| **Community Management**<br>(e.g., transportation, shopping, finances) | |
| **Step 1B: Productivity** | **Importance** |
| **Paid/Unpaid Work**<br>(e.g., finding/keeping a job, volunteering) | |
| **Household Management**<br>(e.g., cleaning, laundry, cooking) | |

| | |
|---|---|
| **Play/School**<br>(e.g., play skills, homework) | |
| **Step 1C: Leisure** | **Importance** |
| **Quiet Recreation**<br>(e.g., hobbies, crafts, reading) | |
| **Active Recreation**<br>(e.g., sports, outings, travel) | |
| **Socialization**<br>(e.g., visiting, phone calls, parties, correspondence) | |

**Step 3: Scoring**

Confirm with the client the 5 most important problems and record them below. Using the scoring cards, ask the client to rate each problem on performance and satisfaction, then calculate the total scores. Total scores are calculate by adding together the performance or satisfaction scores for all problems and dividing by the number of problems.

**Step 4: Re-Assessment**

At an appropriate interval for re-assessment, the client again scores each of the problems selected for performance and satisfaction.

**Initial Assessment**: Occupational Performance

| Problems | Performance 1 | Satisfaction 1 |
|---|---|---|
| **1.**_____ | _____ | _____ |
| **2.**_____ | _____ | _____ |
| **3.**_____ | _____ | _____ |
| **4.**_____ | _____ | _____ |
| **5.**_____ | _____ | _____ |

| **Scoring:** | **Performance Score 1** | **Satisfaction Score 1** |
|---|---|---|
| **Total Score = total performance or Satisfaction score / Number of problems (1-5)** | | |

| **Reassessment:** | | |
|---|---|---|
| **Initial Assessment:** | | |
| **Occupational Performance Problems** | **Performance 2** | **Satisfaction 2** |
| **1.** | | |
| **2.** | | |
| **3.** | | |
| **4.** | | |
| **5.** | | |

| **Scoring:** | **Performance Score 2** | **Satisfaction Score 2** |
|---|---|---|
| **Total Score = total performance or Satisfaction score / Number of problems (1-5)** | | |

**Step 5: Computing Change Scores**

**Change in Performance = Performance Score 2** ☐ **- Performance Score 1** ☐ **=** ☐

**Change in Satisfaction = Satisfaction Score 2** ☐ **- Performance Score 1** ☐ **=** ☐

| **Performance** | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **9** | **10** |
| Not Able to Do it | | | | | | | | | Able to do it extremely well |

| **Satisfaction** | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **9** | **10** |
| Not Able do it | | | | | | | | | Able to do it extremely well |

| **Importance** | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **9** | **10** |
| Not Able to Do it | | | | | | | | | Able to do it extremely well |

Appendix 2: Nowotny Confidence Sub-Scale [62]

Date: _____ Session No.:_____ ID No. _____

**Description:** The Nowotny Confidence Subscale (NCS) of the Nowotny Hope Scale is a self-report of confidence in one's own ability, which uses a 4-point Likert response format of strongly agree to strongly disagree. Content validity was established by literature review and an expert panel. Concurrent validity of the entire scale was established with the Beck Hopelessness Scale at r = -0.47. The internal reliability was 0.83 to 0.92 (Nowotny, 1989).

**Instructions:** Here are some questions, I am going to ask you about how you think about your confidence in your own ability and answer options are: "Strongly disagree, "Disagree", "Agree", or "Strongly agree.". Thinking about your family member(s), Think about your current condition please told me how much you strongly agree, agree, disagree, or strong disagree with the following statements. Are you ready? Okay, Question 1 is... [Read question 1]

**Response Options for variables**

| Strongly Disagree | Disagree | Agree | Strongly Agree |
|---|---|---|---|
| 1 | 2 | 3 | 4 |

| **You feel** | **Strongly disagree (1)** | **Disagree (2)** | **Agree (3)** | **Strongly disagree (4)** |
|---|---|---|---|---|
| 1. You can take whatever happens and make the best of it | ☐ | ☐ | ☐ | ☐ |
| 2. You have a positive outlook. | ☐ | ☐ | ☐ | ☐ |
| 3. You know you can make changes in my life. | ☐ | ☐ | ☐ | ☐ |
| 4. You think you can learn (or you have learned) to adapt to whatever limitations you have (or might have) | ☐ | ☐ | ☐ | ☐ |
| 5. You are ready to meet each new challenge | ☐ | ☐ | ☐ | ☐ |
| 6. You feel the decisions you make get you what you expect. | ☐ | ☐ | ☐ | ☐ |
| 7. When faced with a challenge, you are ready to take action. | ☐ | ☐ | ☐ | ☐ |
| 8. You have confidence in your own ability. | ☐ | ☐ | ☐ | ☐ |

Appendix 3: Patient Health Questionnaire-9 Item (PHQ-9)[63]

**Description:** Patient Health Questionnaire-9 Items (PHQ-9) is used to measure emotional function. The GDS contains nine questions about symptoms and it is a self-rated screening instrument for use in cognitive intact older adults. It has been widely used in older populations. The depression severity levels are: The scores 0 -4 indicate none, the scores between 5 to 9 indicate mild depression; the score between 10-14 indicates moderate depression; the scores between 15 to 19 indicate moderately severe depression, the scores between 20 to 27 indicate severe depression. The internal reliability was .83 to .92. [63,169]

**Instruction:** This survey asks for your views about your health. There is no right and wrong answer. I will read each question and then give you options for your answer." The options are "Not at all, "Several Days," "More than half the day", or "Nearly every day." Are you ready? Okay, Question 1 is...Over the last 2 weeks, how often have you been bothered by any of the following problems?" [Read question 1]

**Responses for variables:**

Not at all 0 Several days 1 More than half the day 2 Nearly every day 3

| Item | Not at all | Several days | More than half the day | Nearly every day |
|---|---|---|---|---|
| 1. Little interest or pleasure in doing things | 0 | 1 | 2 | 3 |
| 2. Feeling down, depressed, or hopeless | 0 | 1 | 2 | 3 |
| 3. Trouble failing or staying asleep, or sleeping too much | 0 | 1 | 2 | 3 |
| 4. Feeling tired or having little energy | 0 | 1 | 2 | 3 |
| 5. Poor appetite or overeating | 0 | 1 | 2 | 3 |
| 6. Feeling bad about yourself or have let yourself or your family down | 0 | 1 | 2 | 3 |
| 7. Trouble concentrating on things, such as reading the newspaper or watching television | 0 | 1 | 2 | 3 |
| 8. Moving or speaking so slowing that other people could have noticed. Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual | 0 | 1 | 2 | 3 |
| 9. Though that you would be better off dead, or of hurting yourself | 0 | 1 | 2 | 3 |
| | *Add column* | _____ + | _____+ | _____ |
| | **TOTAL:** | | | |

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home or get along with other people?

□ Not difficult □ Somewhat difficult
□ Very difficult □ Extremely difficult

Appendix 4: ADCS – Activities of Daily Living Inventory[64]

Information obtained through: ❒ Informant visit ❒ Telephone call

***Instructions:*** *For each question, use the subject's name where S... appears. Before beginning, read the questionnaire guidelines to the informant.*

## ADCS ADL (Family Member)

Subject ID: _____

Date Collected: _____

ADL items: item 1 to item 18

| | |
|---|---|
| 1. In the past 4 weeks did *S* usually manage to find his/her personal belongings at home? | ○ Yes<br>○ No<br>○ Don't Know |
| If yes, which best describes his/her usual Without supervision help performance: | ○ Without supervision help<br>○ With supervision<br>○ With physical help |
| 2. In the past 4 weeks, did *S* select his/her first set of clothes for the day? | ○ Yes<br>○ No<br>○ Don't Know |
| If yes, which best describes his/her usual performance: | ○ Without supervision help<br>○ With supervision<br>○ With physical help |
| 3. Regarding physical getting dressed, which best describes his/her usual performance in the past 4 weeks: (check one) | ○ Dressed completely without supervision or help<br>○ Dressed completely with supervision, but without help<br>○ Needed physical help only for buttons, clasps, or shoelaces<br>○ Needed some help even if clothes needed no fastening or buttoning<br>○ Someone else dressed him/her |
| 4. In the past 4 weeks, did *S* clean a living - , sitting - , or family room? | ○ Yes<br>○ No<br>○ Don't Know |

If yes, which best describes his/her usual performance:

- ○ Without supervision help
- ○ With supervision
- ○ With physical help

5. In the past 4 weeks, did *S* balance his/her checkbook or a credit card statement?

- ○ Yes
- ○ No
- ○ Don't Know

If yes, which best describes his/her usual performance:

- ○ Without supervision help
- ○ With supervision
- ○ With physical help

6. In the past 4 weeks, did *S* ever write things down?

- ○ Yes
- ○ No
- ○ Don't Know

If yes, which best describes the most complicated things that he/she wrote:

- ○ Letters or long notes that other people understood
- ○ Short notes or messages that other people understood
- ○ His or her signature or name

7. In the past weeks did *S* clean a load of laundry?

- ○ Yes
- ○ No
- ○ Don't Know

If yes, which best describes how he/she usually performed:

- ○ Without supervision help
- ○ With supervision
- ○ With physical help

8. In the past 4 weeks, did *S* keep appointments or meetings with other people, such as relatives, a doctor, the hairdresser, etc.?

- ○ Yes
- ○ No
- ○ Don't Know

If yes, which best describes his/her awareness of the verbal meeting ahead of time:

- ○ Usually remembered without written or verbal reminders
- ○ Usually referred to notes, a diary or calendar
- ○ Usually remembered the appointment after verbal reminders on the day
- ○ Usually did not remember, in spite of verbal reminders on the day

9. In the past 4 weeks, did *S* use a telephone?

- ○ Yes
- ○ No
- ○ Don't Know

If yes, which best describes his/her highest level of performance:

- ○ Made all call necessary e.g., after looking in white/yellow pages, or by dialing directory assistance
- ○ Made calls only to well-known numbers, without referring to a directory or list
- ○ Made calls only to well-known numbers by using a directory or list
- ○ Answered the phone and spoke to callers; did not make calls
- ○ Did not answer the phone, but spoke when put on the line

10. In the past 4 weeks, did *S* make him/herself a meal or snack at home?

- ○ Yes
- ○ No
- ○ Don't know

If yes, which best describes his/her highest level of food preparation:

- ○ Cooked or microwaved food, with little or no help
- ○ Cooked or microwaved food, with extensive help
- ○ Mixed or combined food items for a meal or snack, without cooking or microwaving (e.g. made a sandwich)
- ○ Obtained food on his/her own, without mixing or cooking it

11. In the past 4 weeks, did *S* get around (or travel) outside of his/her home?

- ○ Yes
- ○ No
- ○ Don't know

- ○ Traveled alone, went at least 1 mile away from home
- ○ Traveled alone, but remained within 1 mile of home

| | |
|---|---|
| | ○ Traveled only with a chaperone for supervision regardless of the trip<br>○ Traveled only with physical help, regardless of the trip |
| 12. In the past 4 weeks, did *S* talk about current events? (This means events or incidents that occurred during the past month) | ○ Yes<br>○ No<br>○ Don't know |
| 12a) Did *S* talk about regional, national or international events (including sports)? | ○ Yes<br>○ No |
| 12b) Did *S* talk about events outside home involving family, friends or neighbors? | ○ Yes<br>○ No |
| 12c) Did *S* talk about events that occurred at home that he/she took part in or watched? | ○ Yes<br>○ No |
| 12d) Did *S* converse without repeating him/herself or asking the same questions repeatedly? | ○ Yes<br>○ No |
| 13. In the past 4 weeks, did *S* read a magazine, newspaper or book for more than 5 minutes at a time? | ○ Yes<br>○ No<br>○ Don't know |
| 13a) Did *S* usually select or ask for something to read? | ○ Yes<br>○ No |
| 13b) Did *S* usually talk about what he/she read while or shortly after reading (less than an hour)? | ○ Yes<br>○ No |
| 13c) Did *S* usually talk about what he/she read 1-24 hours after reading? | ○ Yes<br>○ No |
| In the past 4 weeks, did *S* watch television? | ○ Yes<br>○ No<br>○ Don't know |
| 14a) Did *S* usually select or ask for different programs or his/her favorite show? | ○ Yes<br>○ No |

14b) Did *S* usually talk about the content of a program while watching it?
- ○ Yes
- ○ No

14c) Did *S* talk about the content of a program within a day (24 hours) after watching it?
- ○ Yes
- ○ No

In the past 4 weeks, did *S* ever go shopping at a store?
- ○ Yes
- ○ No

15a) Did *S* usually select correct items without supervision or help?
- ○ Yes
- ○ No

15b) Did *S* usually pay for items on his/her own?
- ○ Yes
- ○ No

In the past 4 weeks, was *S* ever left on his/her own?
- ○ Yes
- ○ No
- ○ Don't know

16a) Was *S* left away from home, for 15 minutes or longer during the day?
- ○ Yes
- ○ No

16b) Was *S* left at home, for an hour or longer, during the day?
- ○ Yes
- ○ No

16c) Was *S* left at home, for less than 1 hour, during the day?
- ○ Yes
- ○ No

17. In the past 4 weeks, did *S* use a household appliance to do chores? (This does not include a TV.)
- ○ Yes
- ○ No
- ○ Don't know

If yes, ask about all of the following, and check those that apply

- ❒Washer
- ❒Dryer
- ❒Vacuum
- ❒Dishwasher
- ❒Food Processor
- ❒Power tool(s)
- ❒Other:_____
- ❒Toaster Oven
- ❒Range
- ❒Microwave

17a) For the 1 or 2 most commonly used appliances, which best describes how *S* usually used them:
- ○ Without help, and operated all necessary controls
- ○ Without help, but operated only on/off controls
- ○ With supervision (e.g. instruction), but no physical help
- ○ With physical help

18. In the past 4 weeks, did *S* perform a pastime, hobby or game?

- ○ Yes
- ○ No
- ○ Don't know

If yes, ask about all of the following, check all that apply:

- ❒Bingo
- ❒Crosswords
- ❒Art
- ❒Musical Instruments
- ❒Knitting
- ❒Sewing
- ❒Reading
- ❒Gardening
- ❒Golf
- ❒Tennis
- ❒Workshop
- ❒Fishing
- ❒Other:_____

18a) Did *S* require supervision, or help, to perform any of these hobbies?

- ○ No supervision required
- ○ Supervision
- ○ Help

18b) List any hobby(ies) that the subject has lost the ability to perform:
Hobby 1 _____Hobby 2 _____
Hobby 3 _____Hobby 4 _____
Hobby 5 _____Hobby 6 _____
ADL Total Score: _____

19. In the past 4 weeks, did *S* drive a car?

- ○ Yes
- ○ No
- ○ Don't know

If yes, was this:

- ○ *S* drove anywhere, without limitation or help
- ○ *S* drove short distances locally, without limitation or help
- ○ *S* drove short distances locally, only with a passenger who provided input such as directions or instructions

20. During the past 4 weeks, did *S* take his/her medication regularly?

- ○ Yes
- ○ No
- ○ Don't know

If yes, was this:

- ○ Independently
- ○ Only after frequent verbal reminders to do so

| | |
|---|---|
| | ○ Took medication without help if they were set out or arranged to him/her<br>○ Usually or only when someone else gave the medications |
| 21. During the past 4 weeks did *S* usually carry through complex or time-consuming activities to completion? | ○ Yes<br>○ No<br>○ Don't know |
| If yes, which best describes extent to which he/she needed reminders | ○ Rarely or never needed reminders or prompts<br>○ Sometimes needed reminders or prompts (several times per week)<br>○ Needed regular reminders or prompting (daily) |
| 22. During the past 4 weeks, to what extent did *S* initiate complex daily activities or projects (e.g., hobbies, travel) (check one) | ○ Rarely or never needed reminders or prompts<br>○ Sometimes needed reminders or prompts (several times per week)<br>○ Needed regular reminders or prompting (daily) |
| 23. During the past 4 weeks, how long did it usually take *S* to complete complex or time-consuming tasks or activities? (check one) | ○ Normal speed or duration, compared to *S*'s performance over the past few years<br>○ Slower than would have been the case a year or two ago<br>○ Occasionally failed to complete complex tasks or made errors |
| 24. Has EXTENUATING CIRCUMSTANCE (such as a physical health problem, change in residence, change in support network, death of family members, etc.) contributed to a recent alteration in the subject's activities of daily living?<br>If yes, explain: | ○ Yes<br>○ No<br>○ Don't know<br>_____ |

Appendix 5: Components of DEMA[50]

***Session 1 Part 1***:
Meaningful activities engagement overview and assessment: (Functional ability awareness)

- Assess history of meaningful engagement
- Introduce Self-management Tool Kit organization and topics
- Identify and prioritize meaningful activities
- Discuss potential meaningful activity goals
- Introduce 6 topics in Self-management Tool Kit

***Session 2 – 6 Part 1***:
Meaningful activity engagement, autonomy support, goal achievement, emotional needs articulation

- Review meaningful daily activity goals re: how realistic, how achievable
- Discuss potential barriers to enacting activities prioritize needs
- Re-evaluate decisions about priority activities
- Establish individual daily goals
- Identify associations between goals and planned activities
- Choose manageable solutions/activities
- Self-evaluate success and failure
- Re-engage in problem-solving as needed
- Celebrate successes and re-engage in problem-solving
- Throughout, encourage MCI patient articulation of emotional needs
    - Encourage listening by caregivers, encourage MCI patient to share the meaningfulness of activities to participation

***Session 1 – 6 Part 2***:
Self-management Tool Kit 6 topics (1 each session)

*Topic Discussion*: 1) planning meaningful activity, 2) understanding MCI, 3) understanding the treatment of MCI, 4) understanding and dealing with negative emotional responses, 5) learning strategies for living with MCI and dealing with major concerns, and 6) finding available local and national resources

Appendix 6: Guide to Final Interview Questions

| | |
|---|---|
| **1.** Can you tell me a little bit more in more detail about your experiences as part of being part of this program of engagement of meaningful activity program? | **2.** What was your first impression of this program? |
| **3.** How has your engagement with activities that are meaningful to you affected your day to day planning? | **4.** Have there been any other things or people that have helped you remain or be more involved in your daily meaningful activities? |
| **5.** Are there any specific things that you're doing that help keep you involved? | **6.** Are there any other things or people that have been most helpful to you for staying involved in daily meaningful activities? |
| **7.** Have you found anything helpful in coping with that, in coping with having a memory condition? | **8.** Do you have any concerns about your engagement in your activities? |
| **9.** Have you found any meaningful activities that have become easier for you to do? | **10.** Are there particular aspects of the activities that you enjoy the most? |
| **11.** Have there been any activities that have become more difficult for you to do that you've come across? | **12.** What are some things that you worry about the most in terms of the future or your memory condition or your activity engagement? |
| **13.** Tell me about what you have needed help with most to keep engaged in your activities | **14.** Have there been any unhelpful things that people have said or done in your experiences with your memory condition or your memory changes? |
| **15.** What things did you learn from the program that were most helpful? | **16.** Were there any specific things that you learned from the program that you didn't know before? |
| **17.** Are there any things about activity, meaningful activity engagement that you would have liked to know more about such as resources or just knowledge about memory changes? | **18.** Did you find that the session on resources was helpful and took care of everything you needed to know? |

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impairment in an older population. *International psychogeriatrics / IPA.* 2015:1-9.
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Curriculum Vitae

Jennifer L. Ellis

## Experience

Leadership, Business, Healthcare | 20 years

## Education

Indiana University, Indianapolis, IN
Doctor of Philosophy
Major, School of Health and Rehabilitation Sciences
Minor, Health Policy and Management

Des Moines University, Des Moines, IA
Post-Professional Doctor of Physical Therapy

University of Indianapolis, Indianapolis, IN
Master of Science, Physical Therapy
Bachelor of Science
Major, Psychology
Minor, Biology

## Professional Experience

Gentiva Health Services, an affiliate of Kindred at Home — Current
Atlanta, GA | Louisville, KY
Associate Vice President, Research and Business Development

Gentiva Health Services — Atlanta, GA — 2014
AVP, Clinical Practice, Research and Education

Gentiva Health Services — Atlanta, GA — 2011
National Director, Neurologic Specialties

Clinical Consultant, Guest Lecturer — Indianapolis, IN — 2007

Balance Institute of Indiana — Indianapolis, IN — 2005
President, Co-Owner

St Francis Hospital — Beech Grove, IN — 1997
Staff Physical Therapist

Fort Benjamin Harrison — Indianapolis, IN — 1996
Assistant Coordinator, Learning Center

**Select Presentations**

Alabama Assisted Living Association, Statewide Meeting
September 2015; Dothan, AL
Keynote Speaker – *Empowering Older Adults to Improve Physical Activity and Independence*
Ellis, JL.

Alabama Assisted Living Association, Statewide Meeting
March 2015; Dothan, AL
Featured Speaker – *Physical Aspects of Alzheimer's Disease*
Ellis, JL.

American Physical Therapy Association, Combined Sections Meeting
February, 2014; Las Vegas, NV
Poster Presentation – *Functional and Gait Predictors in Persons with Parkinson's Disease Receiving Home-Based Rehabilitation*
Asiri, F.Y., Marchetti G.F., Ellis J.L., Otis L., Sparto P.J., Whitney S.L.

American Physical Therapy Association, Combined Sections Meeting,
January 2013; San Diego, CA
Platform Presentation – *Improvement in Activities of Daily Living Function in Patients with Heart Failure Receiving Home-based Rehabilitation: A Retrospective Cohort Study*
G. Marchetti, F. Asiri, J. Ellis, L. Otis, S. Whitney

2nd International Conference on Design & Modeling in Science, Education & Technology
(DeMsET 2012) and 3rd International Multi-Conference on Complexity, Informatics & Cybernetics (IMCIC 2012) – March 2012; Orlando, FL
DeMset Award: Best in Session
*A Case Study in USA Rehabilitation Service Delivery Using a Classification Regression Tree Analysis to Reduce Balance Impairments and Falls In the Older Population: Impact on Resource Utilization and Clinical Decision-Making*
Lucinda Pfalzer, PT, PhD, FACSM, FAPTA[1], Amy Yorke, PT, MPT, NCS[1], Jennifer Ellis, PT, DPT, MS[2], Laurie Otis, PT, MBA, MHA[2], Bridget Gorski, BS[1]
*1University of Michigan-Flint, Flint, Michigan, 2Gentiva® Health Services, Atlanta, Georgia*

World Confederation For Physical Therapy, World Physical Therapy Association,
June 2011; Amsterdam, Netherlands
Poster Presentation – *Gentiva Safe Strides & AusTOMs Utilization*
S. Whitney, G. Marchetti, J. Ellis, L. Otis

American Physical Therapy Association, Combined Sections Meeting,
February 2011; New Orleans, LA
Platform Presentation – *Balance Changes in Older Adults Receiving Homecare Services*
S. Whitney, G. Marchetti, J. Ellis, L. Otis

The 3rd International Congress on Gait & Mental Function – The Interplay
Between Walking, Behavior and Cognition; February 2010; Washington, D.C.
Poster Presentation – *The Relationship Between Cognition and Gait Performance in Older Adults Undergoing Physical Therapy Intervention in Various Settings*
S. Whitney, G. Marchetti, J. Ellis, L. Otis

American Physical Therapy Association, National Meeting,
June 2009; Baltimore, MD
Platform Presentation – *Balance and Aging in Place*
S. Allred, J. Ellis

Indiana Speech and Hearing Association – State Conference; August 2008; Indianapolis
Invited Lecture – *Vestibular Rehabilitation & Balance Retraining*
J. Ellis

American Physical Therapy Association, National Meeting
June 1996; Milwaukee, WI
Platform Presentation – *Concurrent Validity of the Tinetti Gait and Balance Assessment and Functional Reach as Fall Risk Indicators*
J. Ellis

**Publications**

Lu, YL, Ellis JL, Haase JE, Yang Z, Weaver M, Bakas T, Austrom MG.
Satisfaction with a family-focused intervention for mild cognitive impairment dyads.
*J Nurs Scholarsh*, 2016; in press.

Whitney SL, Marchetti GF, Ellis JL, Otis L.
Outcomes of Usual Versus a Specialized Falls Balance Program in the Home.
*Home Healthcare Now*, 2015 May; 33(5): 265-74.

Asiri FY, Marchetti GF, Ellis JL, Otis L, Sparto PJ, Watzlaf V, Whitney SL.
Predictors of Functional Gait Outcomes for Persons Poststroke Undergoing Home-based Rehabilitation.
*J of Stroke and Cerebraovascular Disease*, 2014; in press: 01-09.

Whitney SL, Marchetti GF, Ellis JL, Otis L, Asiri F, Alghadir A.
Relationship Between Cognition and Gait Performance in Older Adults Receiving Physical Therapy Interventions in the Home.
*J Rehabilitation Research & Development*. 2013; 50: 1089-1098.

Whitney SL, Marchetti GF, Ellis JL, Otis L.
Improvements in Balance in Older Adults Engaged in a Specialized Home Care Falls Prevention Program.
*J Geriatr Phys Ther*. 2013; 36: 3-12.

Pfalzer L, Yorke A, Ellis J, Otis L, Gorski B.
A Case Study in USA Rehabilitation Service Delivery Using a Classification Regression Tree Analysis to Reduce Balance Impairments and Falls in the Older population: Impact on Resource Utilization and Clinical Decision-Making.
e-pub 3/22/2012 in conference proceedings for The Summer 2nd International Conference on Design and Modeling in Science, Education, and Technology: DeMset 2012 at The 16th World Multi-Conference on Systemics, Cybernetics and Informatics: WMSCI 2012, July 17th - 20th, 2012, Orlando, Florida, USA

**Select Activities │ Honors**

American Physical Therapy Association 1995 – present
Section Member: Geriatrics, Neurology

Indiana University Purdue University Indianapolis 2014-2016
Invited Lectures
School of Health and Rehabilitation Sciences
Physician Assistant Program

University of Indianapolis, Krannert School of PT 1998 – 2008
Invited lectures

University of Illinois Medical School 1996 – 2000
Invited lectures

Golden Key International Honour Society

Alpha Eta Society, Des Moines University Chapter

Who's Who Among American Universities & Colleges

Sigma Zeta Honorary Society